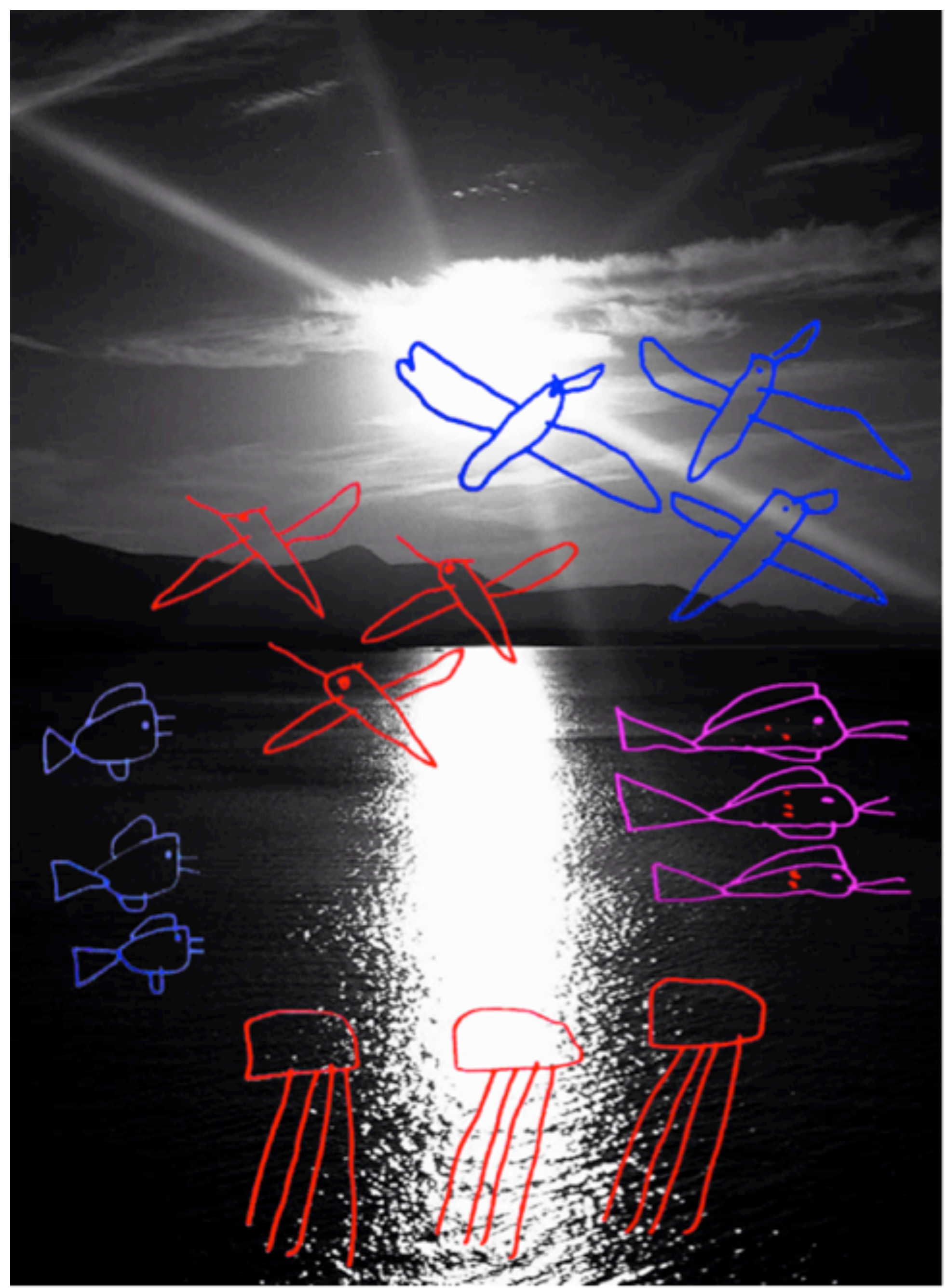


What Works?
Stories of Successful Leadership in the lives, groups and communities of people with intellectual disabilities

Aaron Johannes

Front: collage of images on a photograph, by Ben Simcoe, 2017.
Back: portrait of the author, by Liz Etmanski, 2017.

Gratefully used, with permission.

A dissertation submitted in fulfillment of the requirements for the degree of Doctor in Media and Communication Studies at Vrije Universiteit Brussel

WHAT WORKS?

STORIES OF SUCCESSFUL LEADERSHIP IN THE LIVES, GROUPS AND COMMUNITIES OF PEOPLE WITH INTELLECTUAL DISABILITIES

AARON JOHANNES

2017 - 2018

VUB-Promotoren: dr. Jasmina Sermijn,
prof. dr. Gerrit Loots & prof. dr. Jo Renate Bauwens
Taos advisor: dr. Ginny Belden-Charles

Economische & Sociale Wetenschappen

Dissertation Committee

Promoter

VUB-Promotoren: dr. Jasmina Sermijn & prof. dr. Gerrit Loots
Department of Educational Science
Vrije Universiteit Brussel
Belgium

prof. dr. Jo Renate Bauwens
Vrije Universiteit Brussel
Belgium

Taos advisor: Dr. Ginny-Belden Charles

Exam Committee

Dr. Ginny Belden-Charles
Taos Institute
Chagrin Falls, Ohio
United States

Prof. Dr. Christophe Van Roelen
Vrije Universiteit Brussel
Belgium

Dr. Leen Van Brussel
Vrije Universiteit Brussel
Belgium

Prof. Dr. Geert Van Hove
Ghent University
Ghent

Acknowledgements

> *"What if, instead of responding out of our fear or anxiety, we learned to listen to the heart of those who make us uncomfortable?"* — Lana Wachowski

The most important conversation in Canada, for us as a country and for each of us as individuals, is about Truth and Reconciliation in which we have finally attended to the stories of Indigenous people. It is not only an opportunity to do the right thing now, but for all of us to re-envision ourselves as people completed by those who came before us, who so graciously teach us now. I recognize and acknowledge the Qayqayt First Nation, as well as all Coast Salish peoples, on whose traditional and unceded territories we live, we learn, we play and we do our work which, in this case, includes the research, writing and editing of this dissertation.

My Ph.D. story began in the spring of 2014. Many things about the Taos Institute and their focus on social constructionism and a sense of global scholarly interactions were compelling but I was mostly struck by Ken's idea that the end of a dissertation should not be considered a "defense" – we should let go of this language of competition – and, instead, envision a process of growth and learning which ends with a collegial celebration. This was a completely new idea to me.

Just after I applied, Taos announced a new relational leadership master's program, and I was torn as I had just found this field of studies, and wanted to learn more. When I wrote to say this, Sheila wrote back right away to suggest that her sense from my application was that I was ready for the independence of this level of research, and how would it be if as a potential Ph.D. advisor they introduced me to Ginny Belden-Charles, who led the program in relational leadership. In effect, I could have the best of both worlds, just for the asking.

This kind of responsiveness and kindness has been typical of all my interactions with Taos. So, first of all, I want to thank the Taos Institute and everyone involved in its workings. I was particularly interested in how Taos, with its belief in partnerships and dialogue, worked with global universities like the Vrije Universiteit Brussel. VUB responded to my application with Dr. Jasmina Sermijn and Prof. Dr. Gerrit Loots, both of

whom had been working in another area of interest for me around the concept of the rhizomatic.

Thanks to the three of you in particular. You were superb choices of people for me to work with, and my work is so much better for your influence. Second, I want to thank the Taos Institute and the Free University of Brussels/Vrije Universiteit Brussel for your experiential demonstration of how different parties, and people, may walk together in synergy to become more than the sum of their parts. Other students of both the Taos Institute and VUB are also no small part of this energy and every interaction with any of them has made me certain I am in the right place. Specifically, I must thank Ken and Mary Gergen, Sheila McNamee, Celiane Camargo Borges and Dawn Dole – I know that there are others who are important to the work of Taos but you have all been great models for me in your responsiveness, humility and kindness. In my 60th year, I feel I have a new vision of what being a grown-up looks like! And it has nothing to do with age.

I have been fortunate to work at what I love for 30 years and the Spectrum Society for Community Living folks have been my supporters in this as in all of my other excursions and adventures, in every way, ranging from feedback on my papers to taking calls for me so that I could focus on my research. Thanks in particular to Ernie, Susan, Shelley, Judy, Casey and Kim.

Unexpectedly, I have found a new avocation, teaching at Douglas College in the faculty of Community and Family Studies. While I have never ceased to be amazed to find my colleagues at Spectrum, I found more colleagues in this new work. Thanks to all of my fellow faculty there but especially to Sandra and Lori, who have given me so many great opportunities and gone out of their way to support me. Last but not least in this list, sincere thanks to my students who never stop amazing me as they juggle kids, careers, school and intricately balanced lives – and then think to stop to offer me some kindness. You give me great hope for our future.

The greatest surprise of my academic studies has been the kindness and support of my fellow academics. I had known you were all like this, I would have started this

adventure years ago. Grateful appreciation to Dr. Ken Banks, Dr. Ann-Louise Davidson, Dr. Mark Durieaux, Dr. Gloria Filax, Dr. Kiersten Hatt, Dr. Rachelle Hole, Dr. Francine Jennings, Dr. Michael Kendrick, Dr. Chris Kliewer, Dr. Wendell Kisner, Dr. Rebecca Locke, Dr. Patrick McDonagh, Dr. John O'Brien, Dr. David Pitonyak, Dr. Susan Powell, Dr. Joanna Rankin, Dr. Lyle Romer, Dr. Tim Stainton, and I'm sure others that I have missed. Not a single request for assistance or advice has ever gone unanswered by any of you, and many of you have stopped what you were doing to throw yourselves into helping me.

I also thank my fellow adventurers in this research: Liz Etmanski, Gord Fletcher, Barb Fowke, Barb Goode, Gerry Juzenas, Jerry Laidlaw, Bryce Schaufelberger, Lorie and Dave Sherritt, Ben Simcoe, and Ludo van Pelt, among so many more, some of you for only a few unforgettable hours. Supporting all of us have been a widening circle of friends and allies that are much appreciated: Jules Andre-Brown, Faith Bodner, Vickie Cammack, Angela Clancy, Al Etmanski, Jule Hopkins, Pete LeGrys, Rebecca Pauls, Judy Smith, Emma Van der Klift, Karla Verschoor, Kim Vowell, Norm Kunz and many others. None of you ever hesitated for even a moment any time I asked for help. Thank you.

I want to acknowledge the current leaders of the self-advocacy movement and those who have passed on. I have been amazed at their insights as we have looked at this part of our country's history. Like my late great teacher, Arnold Bennington, you all questioned me closely and then shared unstintingly. Without you this particular research project would not have been possible. I am so grateful.

Before engaging in a PhD I used to read dissertations in which candidates thanked their families and think that was nice. Now, I realize how completely heartfelt it is. I could not have done this without them. Some of you are connected by blood and others are family of choice – thanks to Ronee, Marlow, Michael, Iana, Brenda, Alan, Kirsten, Amanda, Sam, Wulf and in particular to my late mother, Arlene, who passed away during the course of this work. She never quite understood what I was doing but she was behind me all the way – waking up from a coma when someone was talking about my dissertation to tell them how smart I was. I also want to say that I have the

best and most patient in-laws anyone could hope for and part of what is exciting about closing this chapter of my life is that I will get to spend time with you all. I promise.

I want particularly to thank my husband, Gary, and our son, Zev. There are no words for the feeling that you are both always with me and for me, and that together the beating of the story our three hearts makes is stronger than their sum.

A friend taught me a word from her people: oosh-yak-she-thley-its-sue. It is from the Nuuchahnulth tribe, from the west coast of Vancouver Island, and it means, you've done a good thing, and thank you. She says it means this in four different ways. First, she says, we are taught to begin each day in gratitude so we say thank you for our community, our family, for ourselves, for the intention we bring into that day. It signifies the potentiality that brings one into relationship and action for another. So, to all of you who supported this vision, and held the intention and believed in this potential: oosh-yak-she-thley-its-sue. Thank you.

INTRODUCTION:
"ALTERNATIVE FRAMEWORKS OF SENSE"
"THE 'COCOON OF IMPOSSIBILITY"
SENSEMAKING TO SUPPORT LEADERSHIP THROUGH ARTS INFUSED PROCESSES FOR PEOPLE WITH INTELLECTUAL DISABILITIES & INCLUSIVE GROUPS
RÖD TRÅD
A PARALLEL STORY OF LEADERSHIP
AS THE DISCOVERY OF SELF, OTHER & HISTORY - AN AUTOETHNOGRAPHY
WHAT WORKS?
STORIES OF SUCCESSFUL LEADERSHIP
LEADERSHIP IN THE LIVES, GROUPS AND COMMUNITIES OF PEOPLE WITH INTELLECTUAL DISABILITIES
THE NEARLY LOST HISTORY OF THE LOWER MAINLAND COMMUNITY BASED SERVICES SOCIETY
A SUCCESSFUL SELF ADVOCATE INITIATIVE
A META-CIRCLE OF LEADERS WITH INTELLECTUAL DISABILITIES DISCUSS WHAT IS HELPFUL IN THE LEADERSHIP OF THEIR LIVES, GROUPS & IN THEIR COMMUNITIES
SUMMARY:
DISCUSSION & IMPLICATIONS OF THE INTEGRATED FINDINGS
AARON JOHANNES 2017
WITH GRATITUDE TO LIZ, BARB & GORDON

Table of Contents

Dissertation Committee 5

Acknowledgements... 7

List of Figures 18

Dissertation Abstract... 21

Preface: Arnold's story 23

Chapter 1: General Introduction: "Alternative Frameworks of Sense" 29

Abstract & Discussion: This Chapter in Relation to the Dissertation as a Whole 29
Introduction...29
People with Intellectual Disabilities, Worldwide and in British Columbia.................32
What Does Leadership Mean to People with Disabilities? 34
Paying Attention to Accommodations: The Power of Stories in Self-Advocate Leadership 43
Graphic Recording: Thinking in Pictures...44
Allies as Accommodations...44
Defining Leadership...44
Leadership Models: Heroic and Relational...46
Objectives, Research Questions and Methodology...48
Major research questions for focus group discussion. 49
Secondary questions...49
Research Methodology...49
Overview of the Theoretical Underpinnings of the Research Frameworks Applied in this Dissertation...50
Social constructionism in research. 50
Critical disability studies and inclusive research..51
Rhizomatic learning: "Community is the curriculum." 52
Emancipatory Research with people with disabilities. 54
Arts-Based Research and Graphic Recording/Facilitation 55
Gaps in Current Research 58
Research Framework...60
Emergent Issues...62
Thesis Structure...63
References...68

Chapter 2: Ongoing Voices of Isolation and Marginalization of People with Intellectual Disabilities Supported in different Kinds of Programs: The "Cocoon of Impossibility" 81

Abstract 82
Relationship of this Article to the Dissertation 82
Publishing History 84
Introduction 85
Self-advocate autobiographies. 86
Post-deinstitutionalization fragmented narratives of self-advocates. 88
Institutional stories. 90
Narratives from the era of community inclusion 91
Researching inclusion. 93
Taxonomies of segregation 93
Differentiation as exile. 94
Interstitial ruptures 95
Common Stories and Themes 96
Conclusions and Suggestions for Further Research 98
References 100

Chapter 3: Sensemaking to Support Leadership through Arts-Infused Planning Processes for People with Intellectual Disabilities and Inclusive Groups 105

Abstract 106
Relationship of this Article to the Dissertation 106
Publishing History 108
Introduction 108
Background 110
Person-Centred Planning 115
PATH as an exemplary form of person-centred planning. 116
Begin with a dream. 117
Looking back from a future time. 117
NOW? 117
WHO? 117
Building strength. 118
Step by step. 118
How Person-Centred Planning Calls for Social Change 120
Brent’s vision. 120
Julie’s PATH. 124
Person-Centred Planning as Community Organization and Guidance 125
Cheryl’s star raft salons. 127
Ted’s talks. 130
Summary and Implications 134
References 137

Chapter 4: The Nearly Lost History of the Lower Mainland Community-Based Services Society: A Successful Self-Advocate Initiative 145
Abstract 146
Relationship of this Research Article to the Dissertation 146
Introduction 149
Historical Overview 150
Participant Selection 151
Methodology 152
Relevant Literature Search 154
Primary Documents 154
Focus Group Discussions 158
Discussion 167
Summary and Implications for Practice 171
Limitations and Potential for Future Research 176
Conclusion 178
References 180
Chapter 5: A Meta-Circle of Leaders with Intellectual Disabilities Discuss What is Helpful in the Leadership of their Lives, the Groups they are Part of and in their Communities 187
Abstract 188
Relationship of this Article to the dissertation 188
Introduction 190
Theoretical Underpinnings 193
Methodology 194
Inclusive/collaborative research. 194
Research Questions 195
Analysis of Preliminary Data 200
Meta Circle Reflection 201
Review of Pertinent Literature 201
Accessible literature review. 202
Findings: Themes 205
Leadership as a relational activity. 207
Leading together “in a circle.” 208
Marginalized leadership as rhizomatic. 209
The functions of storytelling for self-advocate leaders. 209
Accommodations and communication supports to support inclusion of all kinds of leaders. 212
Adult education. 214

Magic/whimsy. 215
Other themes....215
Discussion 217
Measuring success. 218
Limitations and Future Research 223
Conclusion 224
References 226

Chapter 6: Röd tråd: A Parallel Story of Leadership as the Discovery of Self, Other, and History – An Autoethnography 233

Abstract 234
Relationship of this Article to the Dissertation....235
"A Conversation has Other Laws"....239
"The Loneliness of the Liar" 242
"Silence Not Absence" 242
"Can I Break Through this Film of the Abstract" 258
"If There were a Poetry Where this Could Happen" 259
Arnold Again 260
"This was the Silence I Wanted to Break in You" 261
Dreams 262
Poverty 263
"Till You, and I Who Long to Make This Thing" 264
"From Which Time After Time the Truth Breaks Moist and Green"....266
References 270

Chapter 7: Summary Discussion and Implications of the Integrated Findings 273

Abstract 274
Introduction....274
Summary of this Research 276
The form of this dissertation. 277
The implications of Canada's Truth and Reconciliation Project. 278
The Research Questions 279
Collaborative questions: Explicit and implicit. 280
Gaps in the Existing Research 280
Methodology 281
Inclusive and relational research. 282
Critical disability studies: A lens to interdisciplinary reflection. 283
Results 283
Accommodations. 284
Skilled self-advocate leaders. 284

The pedagogy of leadership learning. 285
Stories. 285
Critical Reflections 289
Truth and reconciliation as a model of changing leadership. 289
Relational leadership – leading in a circle. 291
The impact of a perceived lack of leadership. 291
Measuring efficacy. 292
Becoming researchers. 293
Summary 294
Conclusions 296
Ship of Theseus. 296
Recommendations for Policy and/or Further Research 298
Nothing about us without us. 298
Involving people with ID in research and development. 299
Family dynamics and leadership roles through the lifespan. 300
Narrative focused organizational development. 301
Scholarly Discussion of the Implications of the Integrated Findings 302
References 305

Appendices 311

Appendix A: Example, Graphic Facilitation 312
Appendix B: Participant Recruitment/Information Letter 313
Appendix C: INFORMED CONSENT 315
Appendix D: Ethics Approval 317
Appendix E: Documents of the Lower Mainland Community-Based Services Society 318
Appendix F: Barb Goode's Story of the Eve Case 319
Appendix G: Teaching Video 322
Appendix H: Agenda for "Community Conversation" on Leadership 323
Appendix I: Handout: Planning for Leadership 324
Appendix J: Social Media Research Dissemination Sites 325
Appendix K: Graphic Explanation and Update on our Work for Conferences and Events (Modified) 326

List of Figures

Figure 1. Arn Row and Bill Hiltz (O'Brien, 2016, p. 8). 30
Figure 2. Graphic recording, Portland, Oregon.....................57
Figure 3. Graphic recording, Portland, Oregon.....................57
Figure 4. Aaron, Liz Etmanksi and Asset-Based Community Development Facilitator Joe Erpenbecku.....................57
Figure 5. Graphic, "How This Research Works."....................62
Figure 6. Modified clarity model for people with ID 66
Figure 7. Graphic rendering of this paper for discussion with people with disabilities......................83
Figure 8. Summarizes the autobiographical narratives reviewed. 86
Figure 9. Graphic rendering of this paper for discussion with people with disabilities......................107
Figure 10. Graphic used in invitations to the focal person's network......................113
Figure 11. Steps for the PATH process.....................116
Figure 12. Ty with the PATH his network has helped him imagine and plan together..119
Figure 13. A network of friends finish off the PATH with a group shot; the laptop was the vehicle to include a network member who lived out of town. 119
Figure 14. Graphic, brainstorming Julie's gifts.....................122
Figure 15. Julie's icon – a symbol for what she loves and represents to those who know her......................124
Figure 16. Julie's whole PATH......................125
Figure 17. Cheryl's Star Raft Salon graphic for January. 129
Figure 18. Graphic: Inclusive Research Project: community mapping. 130
Figure 19. Self-advocate brainstorm on who might be invited in by people with disabilities, to dialogues about belonging, and how they might host them. 131
Figure 20. ommunity mapping, Victoria. 132
Figure 21. Community mapping, Victoria, detail. 132
Figure 22. Community mapping – being, becoming, belonging. 133
Figure 23. BACI maps 'sweet spots' in Burnaby.....................134
Figure 24. Relationship of this research article to the dissertation, graphic 148
Figure 25. Graphic, focus group discussion. 158
Figure 26. Graphic rendering of this paper for discussion with people with disabilities......................189
Figure 27. This and similar graphics were used to explain research processes to participants......................198
Figure 28. The flow of workshop agenda that was used in community conversations as a poster to introduce our topics and questions. 199

Figure 29. Graphic worksheet for participants to fill out after discussion, take home to their communities and share with allies and peers.................................200
Figure 30. Graphic recording, focus group, meta-circle of leaders' discussion: Liz Etmanski and Aaron Johannes, July 26, 2016. 205
Figure 31. Graphic of Chapter 6, including portrait of Aaron Johannes by co-researcher Liz Etmanski. 234
Figure 32. A first step in collaboration was to look up 'leader' in the dictionary. 260

"I have an intuitive grasp on a possibility that inclusion can lead to transformation in social and economic relationships." — Judith Snow (2015)

Dissertation Abstract

This research focused on what works to support leadership in the lives, groups, and communities of people with intellectual disabilities as reported by them. A social constructionist lens led to the co-creation of iterative conversations. Dialogic methods and multiple, often synchronous platforms of co-facilitated practices nurtured open-ended examinations of strengths, methods, mysteries, and interdependence. The stance of relational construction moved this research into new terrain through a bricolage of research methods ranging from a literature review of self-advocate voices to qualitative research about their personal and professional leadership histories. The core research question of what works to support people with an intellectual disability (ID) as leaders led to an analysis of inclusive planning strategies, the debriefing of the first successful self-advocate governed service providing agency in North America and a meta-circle of self-advocate leaders discussing themes gathered in “community conversations” over five events. This summative dissertation includes my own autoethnographic reflection on my experience as an ally over two decades. Despite apparent seismic programmatic shifts in how people with ID have been supported over the last half century by rapidly aggregating systems, their current stories of what are nominally called community inclusion programs echo the language, images, and feelings of institutional segregation. The implications of the dissertation are summarized and discussed in the last chapter. Storytelling and relational leadership are found to be predominate methods for people with intellectual disabilities leading to the potential for a new “persistent narrative.” This creates an opportunity to refocus supports, planning and shared accountability through narrative methodologies and generative accommodations such as graphic recording. Relational leadership as a lens through the lifespan of people with ID challenges us with a new way to examine supports, citizenship, and inclusion and asks us to embrace co-construction in our future practices for transformative possibilities.

Preface: Arnold's story

"If I want help, I will ask for it. If I don't ask for it, don't help. That's the way it is with us at People First." In Ottawa, Arnold and I were settling into our hotel and I had tried to help him unpack. He was teaching me the first important lesson of self-advocacy.

I began to volunteer with B.C. People First in 1995. I had met a People First group from Washington State at a conference and came home intent on meeting our provincial group, which the Washington people assured me did exist. Getting involved was not easy, which surprised me. As a volunteer, I was a catch – well known, successful in the field of disability supports, an agency leader, educated, frequently in demand to speak and involved in various change initiatives. Their disinterest was interesting to me, and I kept approaching them, and they kept not calling back. Many years later, when they forgot I did not also have a disability, I got to hear the stories behind the hesitation. They had had several bad experiences with advisors (in People First, people without disabilities who do not have a vote and are available to help board members) and the successes I had had in the world of government and agencies were not what counted for them, and in fact were suspect.

When they did finally call I said that I was happy to do whatever they needed. I assumed they would see my gifts in public speaking, research, curriculum development, networking and project and event organization. Instead, they made me advisor to the treasurer, the role I was least suited for, but it was what they needed most and the treasurer said he was good at math and didn't really need an advisor anyway. It may have been my first experience of the tokenisation I would see them dance with.

Soon after, President Arnold Bennington called to say that we had to go to Ottawa, the capitol of Canada, to explain "our last project." It seemed that the group had received a federal grant and while they had done the work, travelling to four cities and meeting with dozens of people to talk about access to employment, they had lost the original budget, had not tracked expenses, the receipts were now missing, and none of the required outcomes reports had been sent in. Ottawa was angry. In my

organizational world where constant accountability was supported by an infrastructure – file folders and spreadsheets and schedules, I had never seen anything like this.

It seemed they had been ignoring a stream of requests for information and now the federal representative in Ottawa was withholding funds the group needed to continue their work. Suddenly, I was the advisor to the President and the whole board. I began a forensic review, calling up the places they'd presented, creating reports in hindsight, backtracking the dates they'd travelled and presented, getting copies of receipts from hotels they had stayed in and creating estimates for other expenses to use on lost receipt forms.

Ottawa sent plane tickets and Arnold and I, who barely knew each other, met up in Vancouver to fly to the capital. Within minutes he told me that he didn't believe he needed advisors and resented having to bring one just because it was a rule of People First of Canada, developed with someone else in mind and not him. "I am independent," he said, "always have been, always will be."

The morning after discharging me from his room for trying to help, he was waiting for me in the lobby, glasses skewed, shirt untucked, hair unbrushed, a bit of dried food on his chin and wearing the same shirt he'd worn yesterday, buttoned up wrong. In my work with agencies if I had been out with someone who looked like this, I would have been reprimanded. I asked him if he'd like me to help him with his shirt and he looked perplexed, "Didn't we talk about this yesterday?" Right. "You need to listen, Aaron."

At the government building everything was old polished wood, marble and gleaming brass. In a busy office designed to intimidate we were told to wait until we were called for our 15-minute appointment, at which they would decide if they would cross us off their grantees list and we would have to go back to British Columbia and tell the other board members that the revenues to support the singular provincial avenue for a voice for people with ID in our province was gone. The other people waiting looked as if they had been there for a long time. I held on tight to my briefcase full of newly

minted spreadsheets, copies of receipts and recreated receipts, and reports based on interviews with participants and hosts.

“Excuse me, ma’am,” Arnold said loudly in his loud, nasal voice, “But there is nowhere for a wheelchair in your waiting room!” Everyone looked around, suddenly noticing what had been apparent to him right away in this office for services to people with disabilities. He was right. He smiled and waited expectantly. She called someone up and they hefted some chairs to the side so that Arnold’s chair could fit. “Thank you,” he said to her, “We’re all supposed to be welcome here. Please don’t forget!” She nodded.

When at last it was our turn, Arnold turned to me just as we went through the door: “You are new to this,” he said, “And this is a very sensitive area! If I need your help, I will ask you. But I won’t. This is a hot seat! Just let me do the talking.”

I blinked. Everyone always wanted to hear what I was thinking, everywhere I went. *What?* I followed. The receptionist was still staring at us but now she looked as if she felt kind of sorry for me.

In the office, Arnold hurled his wheelchair towards the big desk and stuck out his hand to shake, so that the bureaucrat, who had been reclining almost like someone manning a machine gun, had to get up and come around to take it. Arnold introduced me, and I said hello, and he shook my hand too. “He’s my advisor. In People First our advisors only talk when they’re asked to, so if I need some help I’ll ask him, but I won’t.” *What was I doing here?*

“Mr. Bennington, we brought you to Ottawa to discuss this grant which our department accountants have been unable to finalise the paperwork on for last year’s budget because.”

Arnold held up his hand in an imperious gesture. “Wait, I know you want to hear about our project – and it was a doozy! You will love it. But first I want to tell you a story!” The bureaucrat looked about to say he was a serious person who didn’t listen to stories. “I know, you think you might have heard this one before but trust me, this is a story everyone wants to hear!”

"I was born early to my mom and she was a single mom and I had a cleft palate and a club foot but they made a mistake," he nodded sadly, "and they thought I was . . . I am sorry to say this word but this is the word they used back then – *retarded!*" Arnold's eyes are wide with disbelief. "They didn't know I would grow up and learn to talk and drive a scooter and write a book even and be the President of B.C. People First." The bureaucrat's shoulders lowered, and he leaned back in his chair, and listened.

Our 15-minute appointment had drawn out to nearly an hour and "Bill" – the nameless man who now insisted we call him Bill – waved away his receptionist yet again when she came to point out he was running late.

On behalf of the nation, he had forgiven us our non-reporting, re-instated our good status and given us money for "your important work" for the coming year, as well as extra money to hire someone to make sure we got all our reports in on time for our next project: "It's a little thing, but it matters!" Arnold was now telling him about the annual provincial conference at which many of the presenters would be people with disabilities themselves. Bill noted the dates and said that he was going to look at his schedule to see if there was any chance he could come, as he felt he would learn a lot.

"Oh that's for sure, Bill – you'd really learn a lot!" Arnold said. They both chuckled, playing their parts in this new story.

They shook hands and Bill got up to walk us to the door. He was lingering, he had been obviously having fun with us. He shook my hand too, and leaned in close to whisper, "That was the best support of a person with a disability that I've ever seen. We need people like you here in Ottawa. If you decide to move, let me know." I blinked. I hadn't said a word except, "hello." I hadn't once cracked open my briefcase full of hard won papers.

We moved to the elevator.

"How did I do, Aaron?" he tried to whisper, in his loud voice.

My head was whirling. "You did great, Arnold. You were amazing. How did you even do that?"

He chuckled. "You know what, Aaron – you did good too. For your first time."

How did you even do that? This became a mantra for me over the next 15 years with People First leaders, and then with leaders from other self-advocacy groups, and self-advocates involved in inclusive decision making groups, in my growing fascination with the ways in which they managed their lives, led their groups and movement and interacted in their communities.

All that we are is story. From the moment we are born to the time we continue on our spirit journey, we are involved in the creation of the story of our time here. It is what we arrive with. It is all we leave behind. We are not the things we accumulate. We are not the things we deem important. We are story. All of us. What comes to matter then is the creation of the best possible story we can while we're here; you, me, us, together. When we can do that and we take the time to share those stories with each other, we get bigger inside, we see each other, we recognize our kinship – we change the world, one story at a time.

Richard Wagamese

Chapter 1:

General Introduction: “Alternative Frameworks of Sense”

Abstract & Discussion: This Chapter in Relation to the Dissertation as a Whole

This chapter provides a general introduction to the dissertation. We begin by defining some of the terms used throughout all the parts of this research, such as disability, leadership, accommodations and storytelling, and in this process see that these words and ideas change depending on circumstances, context, purpose and relationship. We then discuss the theoretical underpinnings of the research as a whole: social constructionism, inclusive research methodology and rhizomatic analysis. This section ends with an examination of how people with intellectual disabilities have collaborated in the research and been served by arts-based research methodology. Finally, challenges and gaps in current research and practices are touched upon, and the research framework, objectives and questions are laid out.

Introduction

> *“Society is very much ready for change.*
> *We would be wise to find how to shift the conversation from funding to citizenship. Judith Snow said it best. ‘Society will change when I am in it.’*
> *It starts with finding one’s strength to bring about change.”* — Bill Hiltz (as cited in O'Brien, 2016, p. 8)

At a conference on the facilitation of individualization of planning services for people with disabilities Bill Hiltz is at the front of the room making well-considered points. He confirms these points by citing another authority, the late Judith Snow, a renowned Canadian disability scholar, thus simultaneously using an academic technique and also alluding to a lineage of leadership in the emancipatory movement he is part of. At the front of the room of erudite participants, making informed, inspirational statements, he is demonstrating qualities we recognize as “leadership.”

Figure 1. Arn Row and Bill Hiltz (O'Brien, 2016, p. 8).

However, in the accompanying photograph Bill Hiltz is recognizably "other," with signs of difference which to many people will indicate that he is the kind of person who, not so long ago, might have been institutionalized or segregated in a special school or program. Seeing this, what changes for each of us, depending on our experiences? Further, what happens when we see photos of Judith Snow in her wheelchair, only able to move her head, her wheelchair compelled forward by puffing into a tube?

In previous decades the profound intelligence of someone like Snow might, and did, gain her entry as an exceptional case into our classrooms, workplaces, colleges and universities, and even to the parties we attended and the student debates, despite her physical disabilities. For her this happened with the help of the right supporters (Pearpoint, 1991). Bill, however, would not gain access and we would then miss his voice making a profound statement.

While the characteristics of Bill Hiltz, and people like him, have not particularly changed since they were institutionalized, some now hold vastly different social positions. This is particularly evident when we see them acting effectively in leadership

roles. Yet, others, perhaps most people with ID, must argue for the simplest choices in their lives and this discrepancy in the potential for leadership raises singular questions.

A significant body of evidence demonstrates that our responses to them, out of which come our decisions to include or exclude them, have to do with the construction of their identities by their supports – schools, agencies, and organizations (Munyi, 2012; Yuker, 1970). Confusingly, many of these supports are meant to foster inclusion and empowerment and named as such. For example, "community inclusion programs," that occur within a segregated environment, or "self-advocacy groups" that only meet to do crafts or quilting or learn to cook.

This dissertation is based on stories of what people with intellectual disabilities feel worked for them as leaders in their lives, groups and communities. A critical disability studies lens allows us to see that there are also deeper implications for our culture and for us all, as,

> *when physical and mental autonomy, the ability to think rationally and impartially, and interpersonal separation and distinction are the valued attributes of west subjectivity, then any compromise of control over one's own body, any indication of interdependency and connectivity, or of corporeal instability, are the occasion – for the normative majority – of a deep-seated anxiety that devalues difference.* (Shildrick, 2010, pp. 1–2)

In fact, Shildrick (2010) suggests this is a "dangerous discourse" as it provides a lens not only on the lives and treatment of people with disabilities but interrogates our societal values. One might, like so many parents who find themselves with children who have disabilities, begin to question everything (Feindel, 1995).

For many, an assumption in our culture is that leadership is a rare quality in limited supply, based on individualistic characteristics which perhaps more than any other qualities, exist at the far end of an imaginary meritocratic scale. People at the leadership end are smartest, quickest and most powerful. At the opposite end is our society's consideration of the lives of those assumed to be slowest ("slow learners") and least powerful.

In this dissertation I examine how people with intellectual disabilities perform leadership roles and demonstrate capacity to lead, sometimes in traditional,

individualistic ways that are easily recognizable but more frequently in relational, interdependent ways that emerge from and within the groups they are part of. Their leadership may also look different than we expect. In his book on leadership, Wilfred Drath (2001) uses Mr. Karl as an exemplary leader: "'A leader is someone who never thinks about being a leader,' he once said. 'You just are'" (p. 3). However, as one of the leaders with ID involved in this research constantly asked, "If people think I am a leader, why is it I do not feel like a leader?" If we are to acknowledge and understand their leadership capacity and methods it is important to see the different ways in which people with ID also "just are" leaders so that they can recognize it in themselves and their peers and the communities they are part of can benefit.

People with Intellectual Disabilities, Worldwide and in British Columbia

The World Health Organization (2011) reports that the global number of people with identified disabilities has risen from about 10% in the 1970s to about 15%, with from 2–4% of these experiencing significant disabilities in terms of functioning. These rising numbers have to do with a population that is living longer as well as new methods to measure and articulate disability. Interestingly, the first ever WHO/World Bank World report also breaks down disability in specific ways, each addressed with stories of successful supports and accommodations from different countries (World Health Organization, 2011). In this it is working out of a social model of disability, which posits that disability is a socially created state, as opposed to the more traditional medical model that focuses on diagnosis and deficits.

If disability is a socially created state, it is disconcerting that people with disabilities are more likely to be abused, beaten, raped and sterilized without consent. It is also probable they will be unemployed, live in poverty, and have reduced access to health care and education (Disabled World, 2017). People with ID are considered particularly vulnerable to all of the above, given their relative isolation, communication challenges and cognition. While many of these abuses occurred in historical institutional environments such as British Columbia's Woodland School (McCallum, 2001), now

closed for some 30 years, the Winterbourne View report lists similar abuses within the last few years (Transforming Care and Commissioning Steering Group, 2014).

In Canada, about 3.8 million adult Canadians reported daily limitations due to a disability in 2012, representing almost 14% of the adult population (Statistics Canada, 2015). The Canadian Association for Community Living believes that about 2% of these have an intellectual/developmental disability (Canadian Association for Community Living, n.d.). In 2012 there were 57,250 students with special needs registered in British Columbia's schools (British Columbia Teachers' Federation, 2012). Community Living B.C., the provincial crown corporation responsible for supporting adults with intellectual/developmental disabilities, served 19,757 individuals in 2016, with total operating costs for 2017/18 budgeted at $953.8 million (Government of British Columbia, 2017). Disability supports are big business, and increasingly costly for governments. Disability is defined and re-defined through ever more careful assessments in relation to equally careful policy and budget statements. For example, the discrepancy between the number of students with disabilities (57,250) and adults (19,757) represents reduced supports for adults based not on people having developed adult living skills, but on no longer qualifying for services within a different branch of government.

British Columbia, where much of this research took place, has historically been an outlier in community-based supports to people with ID. It has a long important history of family leadership, was one of the first provinces to close all institutions, and one of the first sites for People First groups, the self-advocacy organization for people with ID (Inclusion BC, n.d.). While this dissertation utilizes global sources, the research's advisory and focus groups and many of its references speak to B.C. as a locality and as indicative of what occurs in other places. However, each locality, province, and country has different policies, procedures and budgets which dramatically affect the daily lives of people with ID. Interestingly, often self-advocate groups seem to exist outside of these concerns and touch on them as little as possible. Working with groups of staff and

agencies in different places can mean radical differences in conditions for inclusion, while self-advocates in those same places have similar issues and goals.

What Does Leadership Mean to People with Disabilities?

The first attempt of people with disabilities to lead their own organization, the League of the Physically Handicapped, dates back to 1935, and the first gathering of People First, the largest organization led by people with ID, was in 1974 in the U.S. (Fleischer & Zames, 2011). However, while a search of the online bookstore, Amazon, for available books on “leader” and “leadership” yields around 160,000 books, when “intellectual disability” is added to “leadership” the number is reduced to four. Further, none of these are about people with ID as leaders but are about their supports. The most important book about supporting people with ID in leadership, Worrell’s (1988) *Advice to Advisors*, has been out of print since 1996.

More specific research exists in academic journals, but is surprisingly sparse given the focus on leadership in the world of disability related supports. Drake (1996), an early researcher, examined the continuing absence of people with disabilities in positions of authority after an earlier report led to policy changes and funding for leadership training programs, and found no increase in leaders with disabilities. His research demonstrates that this was motivated not least by the assumptions of those providing services:

> *Oh no, no, no, because for the simple reason they are mentally retarded. Our ‘consumers’ as you call them are not really capable of participating in the running of anything really I’m afraid.* (Drake, 1996, p. 7)

More recently, a small, growing body of research examines the inclusion and exclusion of people with ID as leaders participating in various ways (Carter, Swedeen, Walter, Moss, & Hsin, 2011; Frawley, 2008; Frawley & Bigby, 2011; Goble, 1999; Goodley, 2000, 2005; O'Brien, 1989; Roets, 2009) and their progress in various mandated positions of shared leadership in organizations and governmental bodies (e.g., Friedman & Beckwith, 2013; Fulton, 2016; Fyson & Fox, 2014; Fyson & Simons, 2003).

There are frequent media stories of people with disabilities as leaders of all kinds. Isabella Springmühl, refused admission in a fashion school, has just been voted one of the top 100 women by the BBC (Khawaja, 2016) for her clothing designs. Others with labels run successful restaurants, or are actors who have seized the rare opportunity for a disabled person to play a disabled person. The first person with a disability is competing in mixed martial arts without accommodations of any kind. Recently a person with a disability created a successful online store to sell whimsical socks. John Franklin Stephens of Special Olympics challenged alt-right raconteur Ann Coulter on social media for disparaging the former president as a “retard” and is generally considered to have won the battle (Sieczkowski, 2012). The late Judith Scott, profoundly disabled, non-verbal and institutionalized most of her life, worked in a community arts program her fibre sculptures became the focus of several monographs, dissertations and global exhibitions (Scott, 2015). However, each of these appears in media of various kinds within the context of singular, somewhat surprising events, without relationship to each other.

Leadership, in the language of disability services, is often called “self-determination.” From the 1980s onward person-centred planning and methods such as PATH, MAPS and Essential Lifestyle Planning were imbued with hope for their potential to support the meaningful involvement of people with intellectual disabilities. One of the cornerstone ideas of such methods is that the person with ID is at the centre of the planning, sharing their choices, hopes and dreams and, in short, is the “leader” of the planning of their own lives (O'Brien & O'Brien, 1998).

However, in school I.E.P.s (individual education plans), in which the person with the disability is to direct their education, “only 12% were considered by school staff to have taken a leadership role” in their meetings (Carter et al., 2011, p. 57). Although school leadership is identified as one of five determining factors for adult outcomes, a 2001 survey of 1,180 special educators found almost no involvement in school leadership within student politics, sports, arts or extracurricular clubs, leading Carter et al. (2011) to state that leadership is “perhaps the least explored and understood aspect

of self-determination among individuals with disabilities” (pp. 57–58). Research since has not been hugely more hopeful about their inclusion as participating leaders (Carter et al., 2011; Frawley, 2008; Frawley & Bigby, 2011; Goble, 1999).

Interestingly, none of these consider how people with disabilities might define and be actors in leadership. Thus, a consideration for statements such as the one about leadership and ID in schools might be to ask what those observing were looking for as signifier as leadership. Possibly, some students were in fact leading, but doing it differently.

There are also many disability-focused groups in which peers meet to work together on various projects and initiatives. Some of these are affiliated with People First, which has now operated for more than 30 years in Canada, with local groups feeding into provincial groups, which come together as a national organization and joins with similar organizations to come together as Inclusion International. Other local groups are independent, while others are part of support organizations with different degrees of arm’s length relationships.

Some groups, for example the Family Support Institute of BC’s (n.d.) selfadvocatenet.com, are cause related. Selfadvocatenet.com creates and supports an online portal for information from around the province about self-advocate life, events, groups and news: “Made by self-advocates with DiversAbilities for self-advocates and their supporters worldwide” (Family Support Institute of BC, n.d., para. 1). A mapping study of similar self-advocate initiatives in Ireland found 43 active projects (Lundström, 2008, p. 5). Globally, there seem to be countless such working groups. This may be related to project based rather than ongoing funding – as long as there is a project, the group can continue with its central work.

In the literature of leadership and ID, there is also an apparent lack of examples of people with ID taking leadership roles in their communities. Yet, almost from the beginning of my research, I heard about people who were, for example, on customer satisfaction committees at their workplaces, or who led or co-managed arts groups and dance troupes, or church and synagogue groups, or headed up volunteer organizations

which did work that was meaningful to them and had little to do with disability per se. In almost every case someone they knew from the community, as opposed to a support service, had organized and compelled their involvement. Once involved, they had many stories of successful leadership (Johannes, 2013).

David and Faye Wetherow's life-work has had to do with fostering key influential connections, moving "from activity to connection," and their capstone model of community building at the social network level focuses on reciprocal, influential relationships:

> *When we catch sight of a person's Interest, it's tempting to move rapidly in the direction of finding an 'activity' that reflects that interest (all too often in the context of 'programs'). It's actually more adaptive and fruitful to think and work systematically in the direction of companionship, connection, and contribution in ordinary community settings.* (Wetherow, n.d., "Move From Activity," para. 1)

They have collected many stories of how unexpected community allies have become key factors in people's lives as successful leaders.

Within disability related supports and government committees many people with disabilities serve on boards or groups where they represent their peers. The recent U.S. survey, *Beyond Tokenism* (Friedman & Beckwith, 2013), was engendered by the concerns of such leaders that they were being tokenized and excluded. It is the largest research study of leaders with disabilities who are on boards of service providing organizations and other governance initiatives. It was responded to by 160 groups that included almost 800 leaders with disabilities, 109 of whom had complex needs such as a requirement for augmentative communication or other assistive devices (Friedman & Beckwith, 2013). People with ID serve as representative leaders in similar situations around the world.

People with ID have also taken the helm of the services that support them to lead good lives. In British Columbia Microboards, small non-profit organizations focused on the goals of one person with a disability, are a popular support model in which the focal person is a leader-participant on their board of Directors, and involved with budgets and planning decisions (Vela Microboards, n.d.). There are now more than

1,200 examples in British Columbia of this successful model of supported self-determination and leadership, some of which have been in operation for as much as 30 years and the model continues to expand across North America, Ireland and Australia. The Lower Mainland Community-Based Services Society was a larger and rarer example of similar thinking about the capability of people with ID to lead their own organizations (Johannes, 2017d).

Over the past decade in particular there has been a growing recognition that people with intellectual disabilities must be involved in decision-making which affects them and this is reflected in law, government guidance, regulation and policy (Inclusion International, 2011) but not consistently in practice. The culmination of these ideas is found in the United Nations (2006) *Convention on the Rights of Persons with Disabilities*, now ratified by 173 countries.

When we begin to seek leadership as a quality within environments and events related to ID, we see the word “leadership” everywhere in the conference programs, documents and popular media attached to people with ID and their supports. We also begin to see leaders in all kinds of different situations. Thus, we find ourselves in an odd and complicated construct in which people with disabilities are said to be leaders, but given only circumscribed and often tokenized roles, or they are leading, but not generally recognized for their cultural capacity for leadership, which allows for their continued exclusion from those roles which have the leverage to promote their concerns.

For example, the Winterbourne View events (Bubb, 2014), in which people with ID were abused by most of the team that worked there, has not been responded to by a call to work on ways to support assertiveness, self-representation and leadership in those with ID but by

> *a new campaign to improve services for people with learning disabilities by encouraging leadership in the learning disability workforce . . . in response to Sir Stephen Bubb’s report ‘Winterbourne View – Time for Change,’ which highlighted lack of leadership as a contributing factor to the abuse at Winterbourne view.* (National Health Service, 2016, para. 1–2)

Research in the area of leadership and ID allows for a critical and generative re-focusing on aspects of their lives which have become calcified within their systems of support. It continues to be difficult to fathom why people with ID, with the same etiology, if one prioritizes that taxonomification, and even the same psycho-socio-economic backgrounds might live lives with absolutely different outcomes in terms of access and aspiration, literally within feet of each other.

Apologists often say that inclusion is "the long game"[1], but in fact a half century of processes have been generally met with positive feedback from community members. In a 1984 paper on a project to re-introduce people who had been moved to institutions back to their communities, the authors talk about taking people with ID on visits to thirty-five schools:

> *Without exception the visits have been a great success. Here are some of the teachers' comments.*
>
> *"This was a never-to-be-forgotten experience. . . . Trainees [persons with ID] danced, sang, and one played the piano very well with one finger . . . photos taken by them."*
>
> *"Highly successful for all concerned . . . students and trainees had friends and acquaintances in common."*
>
> *''Once the initial introductions were over, both groups were left to themselves and friendships developed very easily. The meeting was thoroughly enjoyed by both groups and they felt they learned a lot from each other."*

The insight of the young students being visited is particularly moving, and it is frustrating that someone so young sees, at first glance, the historical situation so clearly:

> *We were learning about a new thing completely. It's not like English and we learn about Shakespeare, because we'd heard about him! We were learning about new people, that they were among us all the time, and they were just around the corner going to this Adult Care Unit which none of us had heard of before.* (McConkey & McCormack, 1984, p. 113)

---

[1] When I posted Colin Goble's 1999 paper on the demystification of roles of staff and people with ID on Facebook today, 18 years after it was published, a social worker colleague responded by saying that the ways in which people are served and supported are "So entrenched and soooooo hard to change, even in places that are considered relatively enlightened. It is definitely the long game."

[2] The Eve case was later brought up as another story that needed to be told before we could move into

This summary of the othering of a group of people, and the sense of excitement and possibility about the potential for inclusion is moving not least because segregation continues in our current systems, under different terminology.

Thirty-one years later, Kliewer, Biklen, and Petersen's (2015) study shows children with disabilities, now theoretically included in their schools, still othered by professionalized systems and presumed incompetence. One, for example, is given a progress report for her "Present Level of Academic Achievement & Functional Performance" (Kliewer et al., 2015, p. 13), which reads, "'Stacy has Down syndrome'" (p. 14). Later, the teacher shares that her position has been, "Okay, these kids are going to [ultimately] be in a [sheltered] workshop, and so you've got to teach them skills that they can do to work in a workshop" (Kliewer et al., 2015, p. 20). Through the intervention of the researchers the teacher comes to see new possibilities for her students to engage the world as active, contributing citizens.

The authors examine the ways in which the identities of people with disabilities are constructed from childhood to create assumptions of incapacity and incompetence, and how these might be challenged. They end their paper with this paragraph:

> *Connectedness and [presumed] competence directly challenge us to leave behind ideologies of deficit and their derivative contexts of pessimism and human control. Instead, we build valued connectedness within local understandings of the individual, further promoting that connectedness in whatever directions it might lead. Rather than blaming an individual's intellect for difficulties with performance, the presumption of competence directs attention to the educator who must find ways that allow for the demonstration of competence. . . . Thus, replacing the label mental retardation with intellectual disability is ultimately a superficial change, as it leaves fully in place the dogma of defectiveness. Instead, connectedness and the presumption of competence contests all that mental retardation has represented and brings us to the end of intellectual disability.* (Kliewer et al., 2015, pp. 23–24)

Such assumptions are even more apparent in adulthood, and the lens of leadership directly challenges these. While we do not expect children to "lead" so much as be engaged in skills development with support, we do expect to "lead" our own lives and in context of whatever our interests and the group's need, to be leaders in other situations. Simplican's research on citizenship and ID relates her own growing

understanding of how this works for people with disabilities, from her first self-advocate conference dinner during which she is partnered with one of the leaders, Charles, who boasts of having eaten three plates at the buffet and four cokes.

> *[He] then related a story about how much he enjoyed sleeping and about a particular day when he was so tired he did not want to get out of bed. I waited for the story's climax, but after a while, I realized that his story was, somehow, complete.*

Simplican (2015) writes, "The people with intellectual and developmental disabilities at this meeting seemed more interested in eating dinner than changing key elements in their lives . . . [and this] left me disappointed for the legitimacy of self-advocacy" (p. 3). As she continues her investigations, she later realizes,

> *[While] I failed to recognize it at the time, Charles was telling me a story about freedom. It took me over a year to understand the political significance behind his boasts about how many cups of Coke he drank, and another three years before I understood the import of his story about sleep . . . [and] I began to see an alternative account of political participation in the combined public presence of nondisabled staff members and people with intellectual and developmental disabilities*. (Simplican, 2015, p. 8)

When Simplican's (2015) parents are no longer able to care for her disabled brother he enters a residence with "sixteen other adults, placed together because of the severity of their intellectual disabilities, exemplified by their shared and total lack of language" (p. 110), and she begins to understand the control that Charles's coke and sleep stories subvert:

> *My understanding of my conversation with Charles and the broader self-advocacy movement — its underlying questions about politics and my own persistent anxiety — thus unfolded as I began visiting my brother in his new institutionalized environment.*
>
> *Throughout the research process, I often returned to personal experiences as a way to think through theoretical challenges. As Kittay poignantly points out, the personal is philosophical is political:*
>
> *It is unsurprising, therefore, that at the same time my brother's life disappeared from the public sphere, I began to see the political and theoretical import of living and acting in public. The more time I spent in his new home — cut off from the community — the more I began to appreciate the radical nature of Charles*

> *having dinner in public. Charles's slow and deliberate counting of his Cokes took on new meaning, as my brother's new institutional guardians banned caffeine from his diet, despite his preference for soda. . . . My brother's life thus made apparent the ways in which the personal is political, as his everyday practices — such as eating, drinking, sleeping, and being with other people — became measured, patrolled, and regimented.* (Simplican, 2015, p. 110)

Simplican (2015) realizes that she has seldom appeared in public with her brother, and that this idea of "the power of eating and meeting in public for self-advocates and allies" (p. 110) is crucial. Harlan Hahn, she recalls, once joked that the commonality of people with disabilities as a minority was their shared "cultural diet" of food from drive-throughs:

> *Eating and living in private — due to physical and stigmatizing barriers — has defined what it has meant to be disabled. Being disabled and public can change what it means to be disabled and, at the same time, change the dynamics of the public – as a physical and political space. Self-advocates can help us reenvision this inclusive future.* (Simplican, 2015, p. 110)

Thus, even to refuse the world of drive-throughs is a radicalized act. As Angela Davis (2006) has said, "Radical simply means 'grasping things at the root'" (p. 1).

If there is a continuum, at the opposite end of eating at a drive through I attended an event organized, designed and facilitated by people with ID to educate their peers, who formed most of the audience. The person supporting them had helped create a slideshow presentation of their ideas, driven them and their materials to the event, and then simply stood back. They engaged the participants in a lively dialogue about "Breaking Down Barriers." They discussed what disability is, employment as a right not a privilege and health care. Most of the people in the room felt they were not heard during medical appointments, or their doctor talked to their caregivers rather than them directly. Almost all of them shared a story about having been invited to say what they wanted in their lives that left them feeling unheard and talked over.

Paying Attention to Accommodations: The Power of Stories in Self-Advocate Leadership

Oliver (1990) and others have discussed the social model of disability in relation to the more traditional medical model, which transfixes one through diagnoses and consideration of one's deficits. In the social model, the assumption is that what "disables" is wholly or partly the social conditions of the environment and culture and these can be changed, depending on the intention to include or exclude (Oliver, 1990).

An important factor in this are possible accommodations. The ADA (Americans with Disabilities Act) states that accommodations are "any modification or adjustment . . . that will enable a qualified applicant or employee with a disability to participate in the application process or to perform essential job functions" (U.S. Equal Employment Opportunity Commission, 2017, What is "reasonable accommodation?," section para. 1). While all of us rely on various supports (such as our smart phones) to accomplish our goals, people with disabilities rely on things like curb cuts for access. For people with ID, who often have memory, cognition and communication challenges, particular accommodations can be necessary and complex. To participate as leaders common accommodations are plain language or large print, alternative ways of "reading" documents, having someone to scribe notes or a helper to explain a meeting's agenda by meeting before.

We can think of storytelling in this sense as an accommodation. There is a long history of interweaving ideas about leadership and the use of stories to create powerful narratives to incite allies and compel social change. Almost any story about leadership can be placed within the framework of Joseph Campbell's (2011) monomyth, the idea of a universal narrative pattern that all cultures have in common. In this, the idea of a the hero at the centre of the framework is often conflated with the leader as the front of action, the person at the podium, but the hero can also be the storyteller. Gardner (2011) writes, "When one thinks of the leader as a storyteller whose newly fashioned stories must wrestle with those that are already operative in the minds of an audience, one obtains a powerful way of conceptualizing the work of leading" (p. xix). A possible

difference for self-advocate leaders in this is that while storytelling might be one approach to leverage for typical leaders, among other approaches such as education, privilege and hierarchy, for people with ID stories may be their strongest framework.

Graphic Recording: Thinking in Pictures

Graphic recording was used as an accommodation in all the events with all of the groups that make up this research, and was also often used as an example of an accommodation that worked but was rarely present. Graphic recording is the synchronous drawing of pictures to record a speech, event or dialogic process. It allows for member checking as participants can watch to see if what they said has been recorded correctly and if they have been represented appropriately. It also allows a group to immediately see and remember what has been discussed, and then build on this together. There was general agreement in every session that the drawings we created of each step in the research allowed people to think bigger, to track what had been talked about, to not have to repeat things, and to organize information and their thoughts better.

Allies as Accommodations

My initial draft research questions were concerned with the idea of allies as an accommodation. Allies for self-advocates support them in their endeavours. In their daily lives many people with disabilities rely on others who assist in what they find difficult or impossible. In People First groups the specific role of advisor is taken by those who do not have disabilities and can be called on for support, but do not have a vote and are not group members (Worrell, 1988, p. 27).

Defining Leadership

Rost (as cited in Uhl-Bien & Ospina, 2012) has said that there are “almost as many definitions of leadership as there are leadership scholars” (p. 45) and definitional variants are often prefaced by a suffix, for example, “relational leadership” or “heroic leadership” or “authentic leadership.” For example, the use of the term “authentic” is indicative of

> *a pattern of leader behavior that draws upon and promotes both positive psychological capacities and a positive ethical climate, to foster greater self-awareness, an internalized moral perspective, balanced processing of information, and relational transparency on the part of leaders working with followers, fostering positive self-development.* (Walumbwa, Avolio, Gardner, Wernsing, & Peterson, 2008, p. 94)

Etymologically, the word “leader” essentially means those who go in front. Historically, within individualistic western cultural assumptions, this has been assumed to indicate a kind of singular, heroic leader within concepts strongly related to capitalist ideology. Mukunda (2013) in his study of leaders through history points out that in early western civilization the initial concepts of leadership almost concurrently arise out of Plato’s Republic and Thucydides’ history of Athens. Plato posited a system to allow for choosing leaders in an ideal city, done in such a way that any individual leader would be replaceable. On the other hand, Thucydides described singularly heroic Athenian leaders, such as Pericles, possessing individualistic, specific, crucial personal skillsets intrinsically related to Athen’s victories and defeats (Mukunda, 2013, pp. 2–3).

Contemporary rethinking of “leadership” is often dated back to Bennis’s 1961 paper, “Revisionist Theory of Leadership” (p. 26), which begins with a quote from Rousseau’s 1762 “The Social Contract”:

> *The problem is to find a form of association which will defend and protect with the whole common force the person and good of each associate, and in which each, while uniting himself with all, may still obey himself alone, and remain as free as before. This is the fundamental problem.*

Bennis (1961) argues for a more modern associational model in which each person has a leadership role working with others on shared goals. All leadership roles and definitions; he suggests, “are concerned with the same pivotal problem — quite possibly the essential problem of the Western tradition — the relationship of the individual and his fulfillment to the demands and constraints of some supra-individual entity” (p. 27).

Scholars have identified four dominant trends in the literature:

- distinguishing leadership from management: managing to *lead*
- trait theories and behaviours: focusing upon *leaders*

- conceptual models: constructing and defining *leadership*
- practicing leadership: considering the act of *leading* (Kay & Venner, 2010).

Leadership Models: Heroic and Relational

Drath (2001) begins by deconstructing how we recognize leadership when we see it, through what he calls a culturally shared “organizing knowledge principle” (p. 7). This allows “individuals and the group as a whole to recognize certain thoughts, words, and actions as being leadership” (Drath, 2001, p. 4). For example, a sign to indicate leadership might be when someone enters a room others fall silent and wait respectfully and expectantly. The leader is the leader as the result of our interactions: “our admiration and appreciation of this kind of leadership, come from a way of thinking about leadership, a way of understanding when leadership is happening, that a group of people can share” (Drath, 2001, p. 4). What is behind and underneath this interaction, he suggests, is our relationship with the leader and those around them. Thus, leadership does not exist independently of us but is the result of developing relationships (Drath, 2001).

Our recognition of the signs that signify leadership on this continuum and where each factor lands is part of a shared recognition of certain “patterns of ideas and underlying assumptions” (Drath, 2001, p. 6) ideas about leadership that form a societal organizing principle. Thus, “leadership principles, as these ways of recognizing leadership will be called, are a shared achievement” (Drath, 2001, p. 6). The idea that leadership exists as a singular quality outside of relationship is only one idea about leadership and “since people interact in many different ways, it is likely that there is not just one master principle from which all other leadership principles are derived” (Drath, 2001, p. 6). Other ways of conveying leadership within other shared understandings are not just “poor relations to this ‘real’ kind of leadership, but are qualitatively different ways of knowing that leadership is happening” (Drath, 2001, p. 7):

> *This approach will allow us to talk about leadership as something that can come into being or go out of being because of the presence or absence of some organizing knowledge principle. People share in these knowledge principles as ways of organizing reality about leadership. If they didn't, a group of people*

> *would never be able to make leadership happen. So there are not as many principles as people, but there is not just one either*. (Drath, 2001, p. 7)

In short, contemporary thinking is that leadership is co-constituted, relational and dynamic rather than a heroic, singular, ongoing quality possessed only by a few. Leadership only exists when we generate it together.

The concept of relational leadership comes closest to describing the action of self-advocate leaders together. In this theory, the dynamic of the interaction between leaders and followers is synergistic and together the people can accomplish more than their combined efforts would have: "In the last decade, as the nature of work has changed, the concept of relationality has deepened, become more explicit, and expanded beyond positional leadership to a concept that emphasizes personal leadership regardless of position or organizational role" (Fletcher, 1994, p. 85).

From a literature review on leadership and intellectual disability (Johannes, 2017c) I return repeatedly to Parker Palmer's (2011) open-ended definition of leadership as possessing these five attributes:

- An understanding that we are all in this together
- An appreciation of the value of "otherness."
- An ability to hold tension in life-giving ways.
- A sense of personal voice and agency.
- A capacity to create community. (pp. 172–173)

Palmer (2011) confronts the idea of otherness not by distancing leadership from it, or even by dissecting it, but by defining part of leadership as coming to appreciative terms with otherness to be true to "the invisible dynamics of the heart that are part of democracy's infrastructure" (p. 13). In thinking about this in the particular case of leaders with intellectual disabilities, Simplican (2015) points out that people with intellectual disabilities "offer us ways to rethink democracy" (p. 8).

This potential for rethinking is timely. Montuori (2010) writes that we are currently in a state of transition that touches almost every aspect of our lives, our countries, our institutions, environment and planet as we leave behind modernist

leadership traditions for less familiar territory in which the "challenge of responsibility is complex" (p. 5):

> *In an age of transition, one of the key dimensions of leadership education is not just learning but unlearning. Many of us were brought up with the images of leadership (implicit theories) of Modernity. Even if we wholeheartedly embrace the new vision, and see ourselves as creative leaders of tribes, our implicit assumptions about leadership may still derive from a past age. For example, Pfeffer and Vega research (Pfeffer & Vega, 1999) show that many organizations are still pervaded by "perverse norms," most notably the idea that good leaders and managers are mean and tough and that their work consists mainly of detached analysis (formulation) backed up by muscle (implementation and enforcement), with some charisma thrown in to differentiate the leaders from the managers.* (p. 5)

Objectives, Research Questions and Methodology

The primary holistic objective of my research project was the collection and thematic organization of stories of a range of people with intellectual disabilities of their successful and satisfying experiences of leadership in their lives, in groups they belonged to and in their communities. The research question was what worked to support leadership in the lives, groups and communities of people with ID. This was important for several reasons. First, there was a gap in the literature in terms of asking people with ID what had worked best for them. Second, the topic resonated for people with ID as they, too, wanted to know what would be helpful to their leadership. Third, given the involvement of people with ID as leaders in various groups, communities and initiatives, and particularly as the Convention on the Rights of Persons with Disabilities is increasingly used as a benchmark by those involved with people with ID, such information can lead to increased understanding. I was also concerned with the secondary objective of examining and documenting what accommodations and methods supported their successes. The idea to focus on stories, to expand the definition of leadership to include leading in one's life, and the forensic review of the Lower Mainland Community-Based Services Society were specific contributions of the self-advocate advisors.

The research questions and methodology went through an ethics review process at Douglas College and were passed on May 2, 2016 (Appendix D). The proposed questions were:

Major research questions for focus group discussion.

"Leadership means to take action. What are some stories about what has been satisfying or successful for you as a leader in:

1) Your life

2) Groups you belong to

3) Your community?"

Secondary questions.

A) How are self-advocate stories shared when they are asked about their successes?

B) What "worked" to make the Lower Mainland Community-Based Services Society successful, and what might be learned that would be useful for similar future projects?

C) What works for self-advocate leaders in the leading of their lives, groups they are part of and in their communities?

Research Methodology

Social constructionist research methods were used in this research in the following ways. First, Gergen's (2015a) concept of research as "future forming" (p. 287) as a tenet of a social constructionist approach fit in nicely with advisory group's concern that our work together be envisioned as an informative, iterative and mutually educative process. To this end we seized opportunities to both collect data during community conversations with people with ID about leadership, and present our findings to interested leaders and their allies. In each community conversation participants used worksheets designed by us to record the actions that they would take when they returned home (see Appendix A).

Within the community of people with ID leadership as a particular factor may be difficult to study within traditional research paradigms because it is so dependent on relationships and a range of contexts beyond what might be considered "normal" leadership. Social constructionism begins with the concept of a dynamic process in which, "virtually all intelligible action is born, sustained, and/or extinguished within the ongoing process of relationship" (Gergen, 2009, p. xv) and reality, and truth, are co-constituted. Our worlds are what we make them, together, continuously, and "even in our most private moments we are never alone" (Gergen, 2009, p. xv).

This research project was intentionally reciprocal in its responsiveness to self-advocate allies and co-facilitators. For example, while not particularly part of the initial research plan, when it became evident that what happened at and to the Lower Mainland Community-Based Services Society continued to be a burning question for self-advocates, it also seemed that understanding the ways in which it had been successful and then disappeared would be a useful example to bring to the research questions.

Overview of the Theoretical Underpinnings of the Research Frameworks Applied in this Dissertation

Social constructionism in research.

My research has been informed by the lens of social constructionist theory as it applies to inclusive formal and experiential adult education and services to adults with ID. These ideas interweave well with theories of inclusive research as broken down by Walmsley and Johnson (2003) in terms of methodologies and ethical perspectives. We can view these inclusive research methods through the lens of key themes in social constructionism identified by McNamee (2010) as

> *a concern with processes of communication as opposed to concern with discovering phenomenon in the "real world." The assumption is that in our daily interactions with others, we construct the relational realities within which we live. Thus, the focus for the constructionist is on joint action . . . or what people do together and what their doing makes. This is a radical departure from the modernist tradition where focus is placed on the individual and his or her private, internal capacities.* (p. 11)

Social constructionist ideologies and research methods offer a number of profitable entryways in the examination of leadership in the lives of people with disabilities, and not least of these is the appreciative consideration of multiple and different concurrent roles within different contexts:

> *A constructionist orientation replaces the conservative leaning of the empiricist orientation with a contextual vision. Rather than seeking irrefutable propositions, the constructionist understands and appreciates the possibilities of multiple understandings, depending on time, culture, and circumstance.* (Gergen, 2015b, p. 52)

For people with ID there is also an abiding interest in how this appreciative sense of multiplicity is allied with pragmatic potential in local places: "constructionists understand that patterns of social life are held together only by negotiated agreements among people" (Gergen, 2015b, p. 52) and the more "perspectives that can be assembled in a situation, the greater the range of possible actions" (p. 52).

Critical disability studies and inclusive research.

One of the newest disciplines in academia, critical disability studies,

> *has seen a remarkable expansion and development in little more than two decades that has moved it decisively away from the rehabilitation studies that previously marked its effective limits to the status of an interdisciplinary subject that is as much at home with theory as with pragmatic solutions. It has become one of the places in which new ideas have evolved most rapidly, suggesting the kind of changes in ways of thinking that can have significant material effects in the everyday reality of people with disabilities.* (Shildrick, 2012, p. 30)

This sense of a discipline that prioritizes pragmatic, solution focused concerns begins with self-reflection on one's own role in research as it applies to those with ID. Goodley (2013) refers to how the idea of "critical" (p. 632) in disability studies, "denotes a sense of self-appraisal; re-assessing where we have come from, where we are at and where we might be going" (p. 632). In this, the work of critical disability scholars' resonate with one of Gergen's (2015a) central statements of social constructionism, that research should be "future forming" (p. 287).

Inclusive research as it known in England, where proponents Walmsley and Johnson (2003) and others have co-created many good examples (e.g., Walmsley, 2011)

of their approach in a range of situations with a variety of individuals and groups, is in the end not merely just a different way of doing research but an emancipatory project that has evolved out of early social role valorization theorizing and the idea that people with disabilities might be co-creators of research rather than merely subjects (Walmsley, 2001). Prior to this, disability related research was "dominated by eugenics, psychology, educational studies and medical investigations, in which people with learning difficulties were tested, counted, observed, analysed, described and frequently pathologised, but never asked for their views" (Walmsley, 2001, p. 188).

Contemporary researchers such as Goodley and Roets have further explored the relational perspectives of inclusive research as it applies to critical disability studies, writing that,

> *disability studies have dallied with many theoretical ideas. Contemporary disability studies occupy and agitate for what Carol Thomas (2007) defines as a transdisciplinary space; breaking boundaries between disciplines, deconstructing professional/lay distinctions and decolonizing traditional medicalized views of disability with socio-cultural conceptions of disablism. Thomas (2007, 73) defines disablism as 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being.' This definition sits alongside other forms of oppression including hetero/sexism and racism. Indeed, . . . the intersectional character of disability is one of a number of reasons why we might conceptualize the contemporary state of the field as critical disability studies.*
>
> *Critical disability studies start with disability but never end with it: disability is the space from which to think through a host of political, theoretical and practical issues that are relevant to all.* (Goodley, 2013, p. 632)

Rhizomatic learning: "Community is the curriculum."

Rhizomatic theory, deriving from Deleuze and Guattari (2005), also offers related alternative ways of thinking about and presenting research. In this I was influenced by ideas such as researchers Sermijn, Devlieger, and Loots's (2008) conceptualization of the self as a continuously constructed story in which the researchers maybe also be actors, which might be presented in alternative, nontraditional forms such as narrative fragments or psychodrama. Cormier (2012), on rhizomatic theory, states,

> *The rhizome is stem of plant [*sic*], like hops, ginger or Japanese bamboo, that helps the plant spread and reproduce. It responds and grows according to its*

> *environment, not straight upwards like a tree, but in a haphazard networked fashion. As a story for learning, it is messy, unstable and uncertain. . . . Our challenge was in learning how to choose, how to deal with the uncertainty of abundance and choice presented by the Internet. In translating this experience to the classroom, I try to see the open web and the connections we create between people and ideas as the curriculum for learning. In a sense, participating in the community is the curriculum.* (para. 2)

Such methods deprivilege the ways in which "categorization and hierarchical ordering" have made it difficult to be true to "difference and singularity" (Loots, Coppens, & Sermijn, 2013, p. 111), thus forming an excellent entryway into research on a population so victimized by categorization. Issues of power and control are addressed by a commonality of adventuring and exploring, which Braidotti (2012) has referred to as nomadology. Such approaches lead to new ways of thinking about the "story" of self-advocates and self-advocacy:

> *When we accept this narrative perspective and assume that people derive their selfhood from the stories they tell about themselves in interaction with the Other, and when we consider therapy as a narrative space where self-stories are coconstructed, we can question what exactly we understand by "the co-construction of a self-story." From a narrative perspective, the story is not only viewed as a metaphor for selfhood: Selfhood is not compared to a story, it is a story (Ricoeur, 1988, 1992). But what kind of story are we talking about here? If selfhood is a coconstructed story, what does that story look like?* (Sermijn & Loots, 2015, p. 534)

Deleuze and Guattari's (2005) famously dense texts allow for an extrapolation of how their concepts might apply to research and education: "the rhizome pertains to a map that must be produced, constructed, a map that is always detachable, connectible, reversible, modifiable, and has multiple entryways and exits and its own lines of flight" (p. 21). Cormier (2012) writes,

> *The philosophy that informs it (see A Thousand Plateaus) posits, among other things, a world that is uncertain. This has great potential, in that it means knowing can be shaped, it is flexible, responsive, resilient – like the rhizome itself. It is also a world where looking for what is 'true' is mostly a question of looking for who has the power to define it as true.* (para. 6)

In terms of intellectual disability, self-determination, issues of access and leadership the field has been enriched by research into the rhizomatic by Griet Roets

and Dan Goodley. Their critical disability studies related work (Goodley, 2000, 2005; Roets, 2008; Roets & Goodley, 2008; Roets, Goodley, & Van Hove, 2007; Roets, Reinaart, Adams, & Van Hove, 2008) furthers and explicates the understanding of the relational perspectives of this kind of research. Roets's (2009) paper, "Unravelling Mr President's nomad lands: travelling to interdisciplinary frontiers of knowledge in disability studies," was particularly a touchstone for my own investigations as it investigates the multi-valent and related layers of leadership in the life of a self-advocate through different contexts and relationships, including her own with him.

Emancipatory Research with people with disabilities.

Oliver (as cited in Barnes & Mercer, 1997) condemned traditional research on and about people with disabilities as "a 'rip-off that has done little, if anything, to confront the social oppression and isolation experienced by disabled people or initiate policies which have made a significant improvement in the quality of their lives" (p. 1). The authors go on to make these points about research that might be called emancipatory:

- the control over all aspects of the research process should lie with the participants;
- the researcher must be accountable to the disabled community;
- the research should adhere to the social model of disability;
- the need for and validity of the concept of 'objectivity' (as demanded in the dominant research paradigms) should be questioned;
- any method may be used to achieve the research aims as long as the previous criteria are met (although qualitative methods are more commonly used);
- personal, lived experiences of disabled people may be a focus (if needed) as long as these are couched firmly within an environmental and cultural context;
- the research should have a meaningful practical outcome for disabled people. (Barnes & Mercer, 1997)

Barnes (as cited in Kramer-Roy, 2015), in other research, states that, “by definition, EDR [emancipatory disability research] should be judged mainly by its ability to empower disabled people through the research process” (p. 1211).

In this research project, participants were continually asked to participate in conversations that changed their thinking about their involvement as leaders, and were able to reconsider whether their roles were effective and useful. This happened in small ways during our community conversations, when, for example, a participant talked about his public role as a spokesperson and the community connections he was making for himself and his peers, and the role he held on the board of the local agency. He was able to see his own significance in a new way. They were not doing him a favour by allowing him this role, but were profiting through his fund-raising and his community connections. He was able to better imagine how he might leverage both roles. He then asked for assistance to create a plan that he could take home to the small community where he lived.

In larger ways, participants of the focus groups were able to see that they had a proud history of accomplishments that had been relatively unrecognized, and to imagine ways to address this, such as giving workshops on their history. This led to a widely distributed video, graphic histories of the Eve case and L.M.C.B.S.S., and plans for webinars to be offered across the province, currently in process.

Arts-Based Research and Graphic Recording/Facilitation

Kalbach (2016), writing about graphics and narratives in user experience talks about their potential for systems change, as they clarify what has happened during the interactions for all those involved, without having to consider cognitive development, communication ability or previous education. In all of the events related to this research, graphic recording and graphic facilitation were used as a research methodology and it is easy to see how the two sets of ideas relate to each other. Brandy Agerbeck (n.d.) has defined graphic facilitation as “the practice of using words and images to create a conceptual map of a conversation . . . drawing a large scale image at the front of the room in real-time”:

> *Graphic facilitation is both process and product. Watching the graphic facilitator creates the map as the group speaks is highly experiential and immediate. It focuses the group as they work, aiding concentration by capturing and organizing their ideas. Everyone can watch their ideas take shape.*
>
> *The manifestation is most resonant with the visual, spatial and systematic thinkers in the group, but it's a powerful tool of recognition for everyone.*
>
> *After the event, the map becomes a document; evidence of the meeting's progress and direction. This resulting conceptual map is an engaging and meaningful tool, because the audience watched its creation in relationship to their experience. Images being emotional and subjective, participants can interpret the image and recall their own "Aha!" moments.* (para. 1–4)

In research such as Mullen and Thompson's (2013) work on communicating complex information about climate change during community educational events the authors demonstrate the capacity for visual communications to convey a continuum of possibility, and in Mullen's (2013) dissertation the authors show how quite complex information can be conveyed and understood through graphics. Similarly, in my own earlier research, 100% of the participants with self-identified intellectual disabilities found that graphic recording was a way for them to be able to more fully participate and keep up in a building, complex conversations (Johannes, 2013). Participants discussed how graphics made it possible for them to "see" what each of them was talking about individually, where they agreed and differed, and to engage in a converging dialogue and decision making processes by staying "on the same page." They found they could "build" on their conversation without having to try to remember what had been said: it was all in front of them.

Figure 2. Graphic recording, Portland, Oregon.

Note. In this meeting in Portland Oregon I recorded the perspective of self-advocate leaders on what conditions they needed in order to "serve community."

Figure 3. Graphic recording, Portland, Oregon.

Note. Liz's translation of this was to draw a group of figures, one of whom is cooking bacon and another is dancing and saying "I don't want a label." They are encircled in a kind of ribbon to indicate they are part of community.

Figure 4. Aaron, Liz Etmanksi and Asset-Based Community Development Facilitator Joe Erpenbecku.

Note. Bringing together a large group of participants from around the province to map community involved projects we found they were particularly interested in Liz's perspective on community and belonging.

Participants with ID enjoyed Liz Etmanski's graphic recordings and the idea that someone with an intellectual disability could convey their words, stories and thoughts as a co-facilitator. The continual loop of positive feedback about our work together left little question about the effectiveness of the arts-based research methods we were

engaged in. Liz's involvement was not only inspiring to me, but a good example of what Patricia Leavy (2015) reflects on when she states that Arts-Based Researchers,

> *seek to bridge and not divide both the artist-self and researcher-self with the researcher and audience and researcher and teacher. Researchers working with these new tools are merging their interests while creating knowledge based on resonance and understanding. . . . Arts-based research practices are a set of methodological tools used by researchers across the disciplines during all phases of social research, including data generation, analysis, interpretation, and representation. These emerging tools adapt the tenets of the creative arts in order to address social research questions in holistic and engaged ways in which theory and practice are intertwined.* (pp. 3–5)

Gaps in Current Research

In almost every way, but particularly in those that matter to them, the actual lives of people with intellectual disabilities have been researched less than one might expect. Rather, most of the research about them has to do with the management of their care, behaviours and aetiologies. Further, the research that might exist on topics of interest is not accessible to them either because it is behind journal firewalls or not in plain language. However, even questions such as do they have the same lifespan and do they get the same health care are only now coming to the forefront, with results that are damning (Walmsley, 2011). In Australia, in the largest research project of its kind, comparative data on avoidable deaths found that the "experience of this population is of premature death, relative over-representation of deaths in young and middle-aged adults, and deaths from preventable causes" (Trollor, Srasuebkul, Xu, & Howlett, 2017, Discussion section, para. 1) such as infections. Even after significant court ordered supports to increase health care responses by a "reasonable adjustment" (Robertson, Hatton, Emerson, & Baines, 2014, p. 5) for people with ID to the average community standard in England, researchers found problematic exclusions, and subtle prejudices and a lack of the accommodations being charged for (Michell, 2012; Walmsley, 2011), while similar studies found the same problems in health care in New Zealand and Canada (Robertson et al., 2014). In the United States the lack of health care, including dental care to an average standard, was deemed so profound by Special Olympics that they created a research project to address it, described in a report titled Promoting

Health for Persons with Mental Retardation — A Critical Journey Barely Begun (Special Olympics, 2001).

So, in some way, it might seem odd to focus on the aspect of "leadership" in the lives of people with ID. However, to not attempt to describe the leadership aspects of their lives and not support them in leadership, to continue not understanding how their variety of leadership works, seems to again relegate them to people who are cared for, rather than people who lead. It leaves them disempowered and unable to address the gaps in their care that are evident.

Arnstein's (1969) early work on the "ladder of citizen participation" (p. 217) demonstrates how people can move from therapeutic service to community leadership. The accruing research evidence about other aspects of their lives is that they would be better served by these entrenched systems if they had more of a voice, and also that they have made repeated attempts to be part of the conversation.

There are many lenses through which one might examine the essential social problem of inclusion, segregation and the lack of access for people with ID. Of these, the lens of leadership which covers the continuum of self-determination (leadership in one's life), working in leadership groups and participating in community as leaders, seems to me to not only potentially clarify their current position but foster inclusive dialogues for change. The situation for people with intellectual disabilities in Canada, one of the countries where they are best supported, is summed up by the Canadian Association for Community Living:

> *Community Living is a simple concept; most of us experience it every day. We live in integrated communities, we work with our peers, and our children go to school with their neighbourhood friends.*
>
> *However, for the 750,000 Canadians who have an intellectual disability, these simple things that we take for granted are not a reality. Although people with intellectual disabilities are capable of learning in regular schools, working at real jobs, and contributing to our communities, they are often excluded simply because of their disability. People with intellectual disabilities want to participate in all of these activities, they want to contribute to society and they want to lead normal lives in the community. Yet 30,000 people with intellectual disabilities still remain in institutions and are unable to fulfil their dreams and ambitions.*

> *Community living, on the other hand, will allow all Canadians, regardless of their disability, to reach their full potential as citizens.* (Canadian Association for Community Living, n.d., Community Living section, para. 2)

Citizenship is defined as a co-constituted "state of being vested with the rights, privileges, and duties of a citizen" ("Citizenship," n.d., Noun section, para. 1) and denotes "the character of an individual viewed as a member of society; behavior in terms of the duties, obligations, and functions of a citizen: an award for good citizenship" (Noun section, para. 2). If we examine various aspects of the lives of people with ID ranging from institutionalization to isolation in communities to lack of education, housing, and jobs – we must ask where the leadership for change is? Why do those in charge talk about "the long game" some 30 years post-institutionalization? Why are the people who are experiencing these gaps not being supported to be heard? Why are they not leading?

Research Framework

> *Who invented this thing called leadership and decided that only some people could be leaders, anyway? Why are we not all leaders, working together? If we talk about this as if it is something just some people do are we just continuing to add to this belief that only some of us can be leaders?* (Focus Group Participant)

The five papers included in this summative dissertation address the largely unexamined phenomenon of the ways in which people who have been labeled as having intellectual disabilities move from the back of the room, assuming they have been invited in the first place, to the podium or to be part of decision-making tables of participatory leaders. People with disabilities involved in this research felt it was important to document the different ways in which they are leaders through stories of experiences that felt were successful and satisfying.

They thought leadership as it is imagined means the lone person at the front of the room, but this is the "old way," while the ways they lead in their lives, groups they are part of and in their communities often depend on interdependent relationships. This examination explores and explicates the two faces of a social problem:

- that people with disabilities are often not included in leadership, or are included but not supported, or are included in ways that feel tokenistic (Hutton, Park, Park, & Rider, 2010; Krebs & Gotto, 2011; Stevens & Ibaūez, 2007);
- that their active, long tradition of successful service as leaders within their lives, self-advocacy and inclusive groups has been unacknowledged and often their successes are forgotten, making it difficult for them to identify their learning as well as their learning needs, which would help them build their future as individuals, leaders and as a movement.

The overall aim of the dissertation is to collect knowledge about the participation of people with intellectual disabilities as leaders in their lives, groups they are part of and in their communities. The dissertation considers four research objectives, together fulfilling five related research questions:

- *A first objective* is to gain insight into how people with ID participate as leaders and “what works” to support their participation.
- *The second research objective* builds on the previous objective, and aims to examine the ways in which people with and without disabilities use the idea of stories and the potential for narratives that are educative and emancipatory.
- *The third objective* follows from the previous objectives as it identifies themes related to leadership which were found in the community conversations; these were then brought to a meta-circle of experienced self-advocate leaders for discussion and reflection.
- *The fourth research objective* of this doctoral dissertation is to explicitly define what might be built on to support increased leadership for people with ID.

The research questions of this dissertation are, if leadership means to take action, what are some stories about what has been satisfying or successful for people with ID as leaders in their lives, groups they are part of and in their communities. To

collect data that addressed these questions it was necessary to look how self-advocates share stories of their successes, and examine "what works?" for self-advocate leaders in the leading of their lives, groups they are part of and in their communities? These questions led to the consideration of where and how people with ID tell and disseminate their stories, currently and historically, and to the examination of the history of the Lower Mainland Community-Based Services Society, as an example of a successful self-advocate-led initiative. Throughout the research, we sought to learn what might be useful for to support leadership for people with ID now and in the future.

From the beginning it was imagined that the research project would rely on arts-based research methodologies to include and equalize participants and researchers by supporting different kinds of cognition. These processes were explained with variations of this graphic:

Figure 5. Graphic, "How This Research Works."
Note. See Appendix A.

Emergent Issues

In all variants of participatory action research there are implications for traditional research methodologies when new questions arise with one's research partners over a longer term project. While no questions arose that did not fit within the research questions or framework, their desired focus on storytelling as a methodology led to implications that needed to be addressed, in terms of how "voice" is treated and

whose voice saying is privileged, to make what statements. Thus, a section of the dissertation because a more extensive literature review of self-advocate voices found in public domains (Johannes, Belden-Charles, & Serminj, 2017).

Nor did I expect to hear so much about how many stories had gone missing or were "nearly missing," and as these stories exemplified many of the ideas related to self-advocate leadership, they became the focus of the paper, *The Nearly Lost History of the Lower Mainland Community-Based Services Society: A Successful Self-Advocate Initiative* (Johannes, 2017d), and of the graphic of Barb Goode's story of the Eve Case (see Appendix F). Both of these had been to all intents and purposes lost within formal systems and archives, and nearly forgotten by the self-advocacy movement.

Thesis Structure

The dissertation is divided into seven chapters as well as appendices. The purpose of the introductory chapter (Chapter 1), "Alternative Frameworks of Sense" (Johannes, 2017b), is to present the research questions, the overall research framework of this dissertation and to place these in context. The next chapters are written as separate articles for publication in journals or anthologies. Chapter 2**, "**Ongoing Voices of Isolation and Marginalization of People with Intellectual Disabilities Supported in Different Kinds of Programs: The 'Cocoon of Impossibility,'" examines two groups of self-advocate stories in terms of what they suggest about being segregated and isolated (Johannes et al., 2017). The first group of stories were written post-institutionalization about institutionalized experiences and the second group is from diverse contemporary self-advocate discourses in which I suggest that self-advocates make interstitial comments about their supports and lives and their continuing segregation and isolation in programs that are nominally concerned with community inclusion. My curiosity in this chapter is about whether self-advocates, who know how important telling their stories are for a number of reasons, are actually being heard. Who is inviting them to speak, and under what conditions is hospitality offered?

Chapter 3, "Sensemaking to Support Leadership Through Arts-Infused Person-Centred and Inclusive Planning Processes" was originally published in a slightly different

form as *Sensemaking Through Arts-Infused Person-Centred Planning Processes* (Johannes, 2016). In this, I give an overview of person-centred planning, which encompasses a number of tools through which people can be heard and can be supported in the leadership of their lives, and then give an overview of how these methods might be extrapolated into community building events, with some representative examples. In these latter groups people with ID and their networks were brought together to have discussions that were important to them. These events were generated by them and conducted as community-based research, and the suggestion is that identified and relatively well-known (in the field of disability supports) qualities of person-centred planning might be extrapolated to be used in these larger gatherings.

Chapter 4, “The Nearly Lost History of the Lower Mainland Community-Based Services Society: A Successful Self-Advocate Initiative” (Johannes, 2017d) explores a debriefing of a successful self-advocate led initiative by creating a chronological analysis using group narrative techniques and graphic recording of their memories. This is a story which was nearly lost to them and to our communities, and looks at what happened before, during and after the creation of the non-profit service providing agency the Lower Mainland Community-Based Services Society. In effect this is an example of successful self-advocate leadership which creates a telling story of their capacity and potential and also suggests how such initiatives must be protected by those who consider themselves allies.

The study presented in Chapter 5, “A Meta-Circle of Leaders with Intellectual Disabilities Discuss What is Helpful in the Leadership of their Lives, the Groups They are Part of and in Their Communities” (Johannes, 2017a), looks at the results of several community conversations about self-advocate leadership through the lens of a focus group which reflected on these ideas. All of the themes which came up in the community conversations and were the object of reflection were aspects of the previous chapters: story, relationship, education, invitation.

Chapter 6, **“**Röd Tråd: A Parallel Story of Leadership as the Discovery of Self and Other – An Autoethnography” (Johannes, 2017e), is a reflection on my own learning

journey through these relational investigations, framed within various voices, narrative, poetic and formal. As my research progressed, I felt the need to look at and validate my own personal experience of these research questions in terms of my own experience of leadership, personal growth, psychological and generational reflection. An important learning for me in this research has been the absolute necessity of all kinds of voices in everything, everywhere, and in this section it felt crucial to include and even welcome my own voice. Chapter 7, Summary discussion and implications of the integrated findings, summarizes the research within a holistic discussion of the findings, research implications and their significance. As well as the summary, there are interpretations, conclusions, recommendations for policy and for future research, and considerations of the limitations of this doctoral dissertation.

Chapters 2–5 each begins with a graphic representation of how each section fits into the overall schema of what works to support leadership in the lives, groups and communities of people with ID. Originally, my research was informed by Sherry Arnstein's (1969) "ladder of citizen participation" (p. 217) but as I explored other diagrammatic models of power and control for other populations I discovered Karsten's (2011) *Participation Models: Citizens, Youth, Online*, subtitled "A chase through the maze," which wrestles with the complexity and multiplicity of these ideas. It begins with Arnstein's 1969 model and then lists 33 others, which take the shape of two and three dimensional ladders, wheels, and maps; some are complex and some are deceptively simple. What is apparent and shared by them all is the need for clarity around who controls what, and the subtleness of what and who shape decision making within the potential for marginalized people to lead.

These models created a good starting point to think about how engagement and participation can be discouraged, tokenized or fostered when systems interact with people they serve. Using Lardner's clarity model, described by Karsten (2011), as a starting point, I mapped out some considerations of this research at the beginning of each chapter.

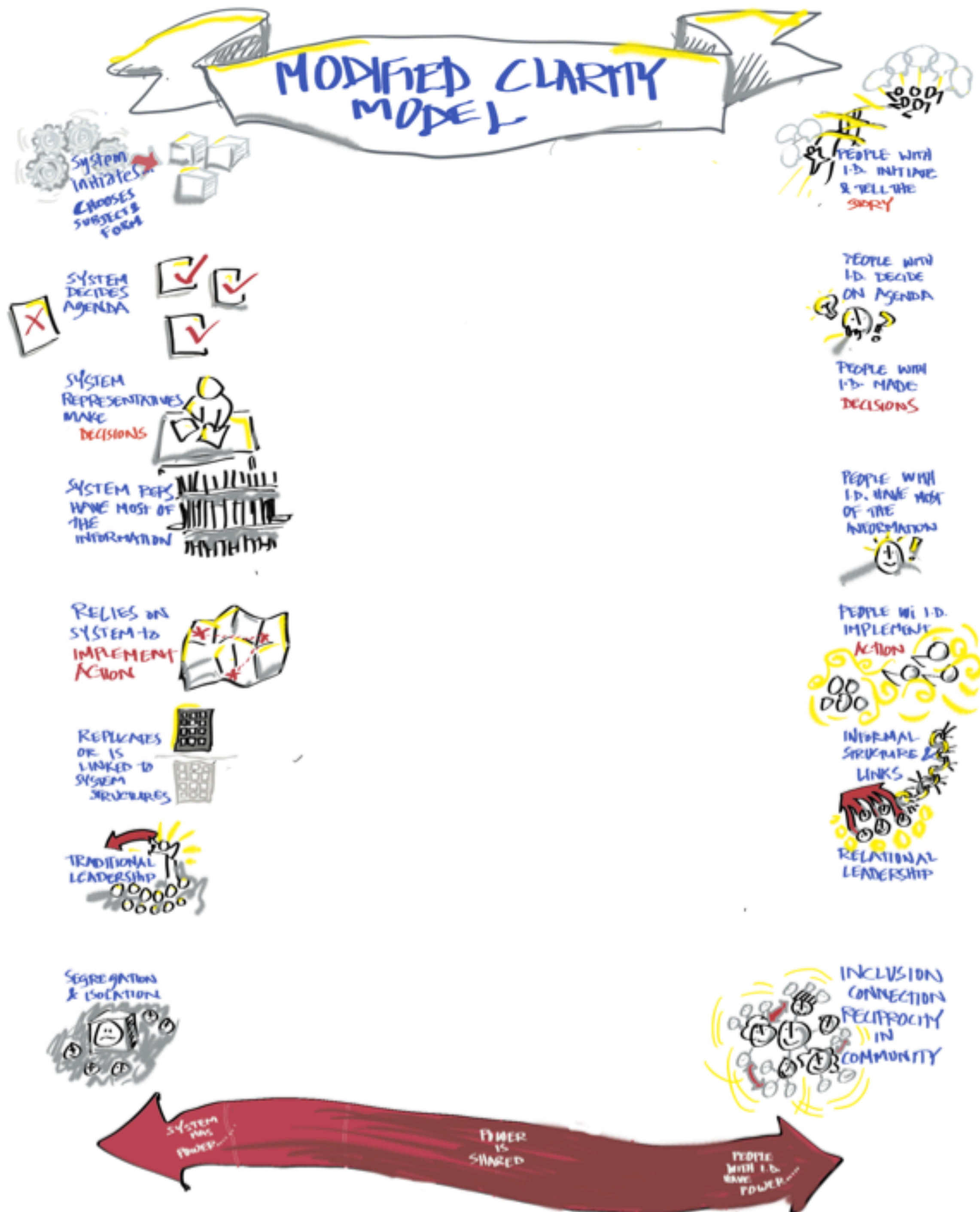


Figure 6. Modified clarity model for people with ID.

For example, mapping out Chapter 2, the paper, “Ongoing voices of isolation and marginalization of people with intellectual disabilities supported in different kinds of programs: the ‘cocoon of impossibility,’” for example, shows us some clear dynamics: i.e., when self-advocates are invited to speak by systems the system remains in control

of the invitation and their story. It also shows us a related area of tension in the question of who holds the information and creates the context. The system holds it as data, collected in many different ways but always privileging the apparently quantitative, and the people receiving support hold the information as stories.

References

Agerbeck, B. (n.d.). *Introduction to graphic facilitation*. Retrieved from http://www.loosetooth.com/gf/intro.htm

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Planning Association, 35*(4), 216–224. http://dx.doi.org/10.1080/01944366908977225

Barnes, C., & Mercer, G. (1997). Breaking the mould? An introduction to doing disability research. In C. Barnes, & G. Mercer (Eds.), *Doing disability research* (pp. 1–14). Leeds, United Kingdom: The Disability Press.

Bennis, W. G. (1961). Revisionist theory of leadership. *Harvard Business Review, 39*(1), 26–36, 146–150.

Braidotti, R. (2011). *Nomadic theory: The portable Rosi Braidotti*. New York, NY: Columbia University Press.

British Columbia Teachers' Federation. (2012). *2012 BC education facts*. Retrieved from http://www.bctf.ca/uploadedFiles/Public/Publications/2012EdFacts.pdf

Bubb, S. (2014). *Winterbourne view – time for change: Transforming the commissioning of services for people with learning disabilities and/or autism.* Retrieved from https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf

Campbell, J. (2011). *Myths to live by: The collected works of Joseph Campbell* [Electronic version]. Retrieved from https://www.amazon.com/Myths-Live-Collected-Joseph-Campbell-ebook/dp/B00537W8I2/ref=sr_1_1?s=digital-text&ie=UTF8&qid=1500326259&sr=1-1&keywords=myths+to+live+by

Canadian Association for Community Living. (n.d.). *Definitions & terminology.* Retrieved from http://www.cacl.ca/about-us/definitions-terminology

Carter, E. W., Swedeen, B., Walter, M. J., Moss, C. K., & Hsin, C.-T. (2011). Perspectives of young adults with disabilities on leadership. *Career Development for Exceptional Individuals*, *34*(1), 57–67. http://dx.doi.org/10.1177/0885728810387411

Citizenship. (n.d.). In *Dictionary.com unabridged*. Retrieved from http://www.dictionary.com/browse/citizenship

Cormier, D. (2012, August 16). Trying to write rhizomatic learning in 300 words [Web blog post]. Retrieved from http://davecormier.com/edblog/2012/08/16 /rhizomatic-learning-and-moocs-assessment/

Davis, A. (2006, April). *Moe lectureship in women's studies*. Retrieved from https://gustavus.edu/gws/events/angeladavisflier.pdf

Deleuze, G., & Guattari, F. (2005). *A thousand plateaus: Capitalism and schizophrenia* (11th ed., B. Massumi, Trans). Minneapolis, MN: University of Minnesota Press.

Disabled World. (2017, January). *Disability statistics: Facts on disabilities and disability issues*. Retrieved from https://www.disabled-world.com/disability/statistics/

Drake, R. F. (1996). Charities, authority and disabled people: A qualitative study. *Disability and Society*, *11*(1), 5–24. http://dx.doi.org/10.1080 /09687599650023290

Drath, W. (2001). *The deep blue sea: Rethinking the source of leadership* [Electronic version]. San Francisco, CA: Jossey-Bass.

Family Support Institute of BC. (n.d.). *Self advocate net*. Retrieved from http://selfadvocatenet.com/

Feindel, P. A. (1995). *Narrating resistance: A B.C. mother's story of disability rights activism.* Retrieved from http://summit.sfu.ca/system/files/iritems1/9046 /etd4102.pdf

Fleischer, D. Z., & Zames, F. (2011). *The disability rights movement: From charity to confrontation.* Philadelphia, PA: Temple University Press.

Fletcher, J. K. (1995). The relational practice of leadership [Electronic version]. In M. Uhl-Bien, & S. M. Ospina (Eds.), *Advancing relational leadership research* (pp. 83–106). Retrieved from https://www.amazon.com/dp/B01MR36YIL/ref=rdr kindle_ext_tmb

Frawley, P. (2008). *Participation in government disability advisory bodies in Australia: An intellectual disability perspective* (Doctoral dissertation, La Trobe University). Retrieved from http://arrow.latrobe.edu.au:8080/vital/access/services/Download/latrobe:19719/SOURCE1

Frawley, P., & Bigby, C. (2011). Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia. *Journal of Intellectual & Developmental Disability, 36*(1), 27–38. http://dx.doi.org/10.3109/13668250.2010.549465

Friedman, M., & Beckwith, R.-M. (2013, July). *Beyond tokenism: People with complex needs in leadership roles.* Retrieved from http://www.beyondtokenism.com/wp-content/uploads/2016/05/Michigan-Report-Final-Public-copy-2016.pdf

Fulton, K. (2016). *The goal is citizenship not the NDIS*. Retrieved from http://www.centreforwelfarereform.org/library/type/text/the-goal-is-citizenship-not-the-ndis.html#.V3uClVSQFft.facebook

Fyson, R., & Fox, L. (2014). Inclusion or outcomes? Tensions in the involvement of people with learning disabilities in strategic planning. *Disability & Society, 29*(2), 239–254. http://dx.doi.org/10.1080/09687599.2013.776491

Fyson, R., & Simons, K. (2003). Strategies for change: Making valuing people a reality. *British Journal of Learning Disabilities, 31*(4), 153–158. http://dx.doi.org/10.1111/j.1468-3156.2003.00251.x

Gardner, H. E. (2011). *Leading minds: An anatomy of leadership* [Electronic version]. Retrieved from https://www.amazon.ca/Leading-Minds-Leadership-Howard-Gardner/dp/0465027733

Gergen, K. J. (2009). *Relational being: Beyond self and community* [Electronic version]. Retrieved from https://www.amazon.ca/dp/B005BP2G4M/ref=rdr_kindle_ext_tmb

Gergen, K. J. (2015a). From mirroring to world-making: Research as future forming. *Journal for the Theory of Social Behaviour, 45*(3), 287–310. Retrieved from http://works.swarthmore.edu/cgi/viewcontent.cgi?article=1796&context=fac-psychology

Gergen, K. J. (2015b). From propositions to practice pedagogy for life as process. In T. Dragonas, K. J. Gergen, S. McNamee, & E. Tseliou (Eds.), *Education as social construction: Contributions to theory, research and practice* (pp. 49–61). Chagrin Falls, OH: Taos Institute/WorldShare Books.

Goble, C. (1999). "Like the secret service isn't it." People with learning difficulties, perceptions of staff and services: Mystification and disempowerment. *Disability & Society*, *14*(4), 449–461. http://dx.doi.org/10.1080/09687599926064

Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties: The politics of resilience.* Berkshire, England: Open University Press.

Goodley, D. (2005). Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities, 9*(4), 333–343. http://dx.doi.org/10.1177/1744629505059267

Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society, 28*(5), 631–644. http://dx.doi.org/10.1080/09687599.2012.717884

Government of British Columbia. (2017, March 8). *Factsheet: Community living BC.* Retrieved from https://news.gov.bc.ca/factsheets/community-living-bc

Hutton, S., Park, P., Park, R., & Rider, K. (2010). Rights, respect and tokenism: Challenges in self-advocacy. *Journal on Developmental Disabilities, 16*(1), 109–113.

Inclusion BC. (n.d.). *Advocacy support.* Retrieved from http://www.inclusionbc.org/about-us/history

Inclusion International. (2011). *Profile and annual report for years ended 31 December 2010 and 31 December 2011.* Retrieved from http://inclusion-international.org/wp-content/uploads/2010/05/II-AR-2010-2011-FINAL.pdf

Johannes, A. (2013). *People with intellectual disabilities as leaders: Collaboratively identifying strategies for success, using graphic facilitation* (Master's thesis). Athabasca University, Canada.

Johannes, A. (2016). Sensemaking through arts-infused person-centred planning processes. In B. Agerbeck, K. Bird, S. Bradd, & J. Shepherd (Eds.), *Drawn together through visual practice: An anthology* (pp. 63–74). Retrieved from http://www.loosetooth.com/bikablo/Drawn_Together_Haussmann.pdf

Johannes, A. (2017a). *A meta-circle of leaders with intellectual disabilities discuss what is helpful in the leadership of their lives, the groups they are part of and in their communities*. Unpublished manuscript.

Johannes, A. (2017b). *Alternative frameworks of sense*. Unpublished manuscript.

Johannes, A. (2017c). *Literature review – intellectual disability and leadership*. Unpublished manuscript.

Johannes, A. (2017d). *The nearly lost history of the Lower Mainland Community-Based Services Society: A successful self-advocate initiative*. Unpublished manuscript

Johannes, A. (2017e). *Röd tråd: A parallel story of leadership as the discovery of self and other – an autoethnography*. Unpublished manuscript.

Johannes, A., Belden-Charles, G., & Serminj, J. (2017). Ongoing voices of isolation and marginalisation of people with intellectual disabilities supported in different kinds of programs: The “cocoon of impossibility.” *Research and Practice in Intellectual and Developmental Disabilities, 1,* 42–53. http://dx.doi.org/10.1080/23297018.2017.1309986

Kalbach, J. (2016). *Mapping experiences: A complete guide to creating value through journeys, blueprints, and diagrams.* Sebastopol, CA: O'Reilly.

Karsten, A. (2011, July). *Participation models: Citizens, youth, online: A chase through the maze.* Retrieved from http://www.nonformality.org/participation-models

Kay, S., & Venner, K. (Eds.) (with Burns, S., & Schwarz, M.). (2010). A cultural leadership reader. Retrieved from http://www.co-creatives.co.uk/wp-content/uploads/2014/12/a_cultural_leadership_reader_201007051349381.pdf

Khawaja, A. (2016, November 29). 100 women 2016: Designing clothes for people with Down's syndrome. *BBC News.* Retrieved from http://www.bbc.com/news/world-latin-america-38132503

Kliewer, C., Biklen, D., & Petersen, A. (2015). At the end of intellectual disability. *Harvard Educational Review, 85*(1), 1–28.

Kramer-Roy, D. (2015). Using participatory and creative methods to facilitate emancipatory research with people facing multiple disadvantage: A role for health and care professionals. *Disability & Society, 30*(8), 1207–1224. http://dx.doi.org/10.1080/09687599.2015.1090955

Krebs, B., & Gotto, G. (2011). Beyond tokenism. *Research to Practice in Self-Determination,* 1, 24–26. Retrieved from http://ngsd.org/sites/default/files /research_to_practice_sd_-_issue_1_0.pdf

Leavy, P. (2015). *Method meets art*: *Arts-based research practice* (2nd ed.) [Electronic version]. Retrieved from https://www.amazon.ca/Method-Meets-Art-Second-Arts-Based-ebook/dp/B00T583ATQ/ref=sr_1_1?s=books&ie=UTF8&qid =1500333541&sr=8-1&keywords=kindle+Method+Meets+Art%3A+Arts-Based+Research+Practice

Loots, G., Coppens, K., & Sermijn, J. (2013). Practising a rhizomatic perspective in narrative research [Electronic version]. In M. Andrews, C. Squire, & M. Tamboukou (Eds.), *Doing narrative research* (2nd ed., pp. 108–125). http://dx.doi.org/10.4135/9781526402271.n6

Lundström, F. (2008). *Mapping self-advocacy initiatives for people with intellectual disability in Ireland*. Retrieved from http://www.citizensinformationboard.ie /downloads/advocacy/SelfAdvocacyMapping_rpt_Oct2008.doc

McCallum, D. (2001, August). *The need to know: Administrative review of Woodlands School.* Retrieved from http://www.inclusionbc.org/resources/need-know-administrative-review-woodlands-school

McConkey, R., & McCormack, B. (1984). Changing attitudes to people who are disabled: A review of research and implications for mental handicap. *Mental Handicap, 12*(3), 112–114. http://dx.doi.org/10.1111/j.1468-3156.1984.tb00231.x

McNamee, S. (2010). Research as social construction: Transformative inquiry. *Saúde & Transformação/Social Health & Social Change, 1*(1), 9–19.

Michell, B. (2012). Checking up on des: My life my choice's research into annual health checks for people with learning disabilities in Oxfordshire. *British Journal of Learning Disabilities, 40*(2)*,* 152–161. http://dx.doi.org/10.1111/j.1468-3156.2012.00742.x

Montuori, A. (2010). Transformative leadership for the 21st century reflections on the design of a graduate leadership curriculum. *ReVision, 30*(3/4), 4–14.

Mukunda, G. (2013). *Indispensible: When leaders really matter.* Boston, MA: Harvard Business Review Press.

Mullen, K. C. (2013). *I see what you mean: Visual and participatory climate change communication.* Department of Human Dimensions, Natural Resources, Colorado State University.

Mullen, K. C., & Thompson, J. L. (2013). Graphic recording: Using vivid visuals to communicate climate change. *The Electronic Journal of Communication, 23*(3).

Munyi, C. W. (2012). Past and present perceptions towards disability: A historical perspective. *Disability Studies Quarterly*, *32*(2). Retrieved from http://dsq-sds.org/article/view/3197/3068

National Health Service. (2016, February 24). *New campaign promotes leadership in learning disability services*. Retrieved from https://www.hee.nhs.uk/news-events/news/new-campaign-promotes-leadership-learning-disability-services

O'Brien, J. (1989). What's worth working for? Leadership for better quality human services. In V. Bradley, & H. Bersani (Eds.), *Improving the quality of services for people with developmental disabilities: It's everybody's business.* Baltimore, MA: Paul Brookes.

O'Brien, J. (2016). *Reflections on common threads: Changing stories . . . stories of change.* A conference on Independent Facilitation sponsored by The Ontario Independent Facilitation Network. Retrieved from http://www.oifn.ca/newsite /wp-content/uploads/2016/09/Common-Threads-2016-1.0-screen.pdf

O'Brien, J., & O'Brien, C. L. (1998). *A little book about person centered planning*. Toronto, Canada: Inclusion Press.

Oliver, M. (1990, July 23). *The individual and social models of disability*. Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with Established Locomotor Disabilities in Hospitals. Retrieved from http://disability-studies.leeds.ac.uk/files/library/Oliver-in-soc-dis.pdf

Palmer, P. (2011). *Healing the heart of democracy: The courage to create a politics worthy of the human spirit.* San Francisco, CA: Jossey-Bass.

Pearpoint, J. (1991). *From behind the piano: The building of Judith Snow's unique circle of friends*. Toronto, Canada: Inclusion Press.

Robertson, J., Hatton, C., Emerson, E., & Baines, S. (2014). The impact of health checks for people with intellectual disabilities: An updated systematic review of evidence. *Research in Developmental Disabilities, 35*(10), 2450–2462. http://dx.doi.org/10.1016/j.ridd.2014.06.007

Roets, G. (2008). *Connecting activism with academia: A postmodernist feminist perspective in disability studies* (Doctoral dissertation, Ghent University). Retrieved from https://biblio.ugent.be/publication/4167118

Roets, G. (2009). Unravelling Mr President's nomad lands: Travelling to interdisciplinary frontiers of knowledge in disability studies. *Disability & Society, 24*(6), 689–701. http://dx.doi.org/10.1080/09687590903160142

Roets, G., & Goodley, D. (2008). Disability, citizenship and uncivilized society: The smooth and nomadic qualities of self-advocacy. *Disability Studies Quarterly, 28*(4). http://dx.doi.org/10.18061/dsq.v28i4.131

Roets, G., Goodley, D., & Van Hove, G. (2007). Narrative in a nutshell: Sharing hopes, fears, and dreams with self-advocates. *Intellectual and Developmental Disabilities, 45*(5), 323–334. http://dx.doi.org/10.1352/0047-6765(2007)45[323:NIANSH]2.0.CO;2

Roets, G., Reinaart, R., Adams, M., & Van Hove, G. (2008). Looking at lived experiences of self-advocacy through gendered eyes: Becoming femme fatale with/out 'learning difficulties.' *Gender and Education, 20*(1), 15–29. http://dx.doi.org /10.1080/09540250701763319

Scott, J. (2015). *Judith and Joyce Scott.* Retrieved from http://judithandjoycescott.com/

Sermijn, J., Devlieger, P., & Loots, G. (2008). The narrative construction of the self: Selfhood as a rhizomatic story. *Qualitative Inquiry, 14*(4)*,* 632–650. http://dx.doi.org/10.1177/1077800408314356

Sermijn, J., & Loots, G. (2015). The cocreation of crazy patchworks: Becoming rhizomatic in systemic therapy. *Family Process, 54*(3), 533–544. http://dx.doi.org/10.1111 /famp.12119

Shildrick, M. (2010). *Dangerous discourses of disability, sexuality and subjectivity.* London, United Kingdom: Palgrave Macmillan.

Shildrick, M. (2012). Critical disability studies. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 30–41). New York, NY: Routledge.

Sieczkowski, C. (2012). John Franklin Stephens, special olympics athlete, pens open letter to Ann Coulter over "retard" remark. *Huffpost*. Retrieved from http://www.huffingtonpost.com/2012/10/24/ann-coulter-retard-john-franklin-stephens-special-olympics-open-letter_n_2008538.html

Simplican, S. C. (2015). *The capacity contract: Intellectual disability and the question of citizenship.* Minneapolis, MN: University of Minnesota Press.

Special Olympics. (2001, March). *Promoting health for persons with mental retardation — a critical journey barely begun.* Retrieved from http://staging.specialolympics .org/uploadedFiles/LandingPage/WhatWeDo/Research_Studies_Desciption_Pages/promoting_health_for_persons_with_ID.pdf

Statistics Canada. (2015, November 30). *Disability in Canada: Initial findings from the Canadian survey on disability.* Retrieved from http://www.statcan.gc.ca/pub/89-654-x/89-654-x2013002-eng.htm

Stevens, J., & Ibaũez, B. (2007). *Reducing barriers to employment for people with significant disabilities: Best practice guide.* Retrieved from http://www.wowonline.org/ourprograms/dc/dcjobscouncil/documents/ReducingEmpBarriersIndlsDisabilities.pdf

Trollor, J., Srasuebkul, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open, 7*(2)*.* Retrieved from http://bmjopen.bmj.com/content/7/2/e013489

Uhl-Bien, M., & Ospina, S. M. (2012). *Advancing relational leadership research: A dialogue among perspectives* [Electronic version]. Retrieved from https://www.amazon.com/Advancing-Relational-Leadership-Research-Perspectives/dp/1617359211

United Nations. (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-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

U.S. Equal Employment Opportunity Commission. (2017, February 24). *Americans with disabilities act: Questions and answers.* Retrieved from https://www.ada.gov /archive/q&aeng02.htm

Vela Microboards. (n.d.). *Individualized Funding is another way to access funding.* Retrieved from http://www.velacanada.org/

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society, 16*(2)*,* 187–205. http://dx.doi.org /10.1080/09687590120035807

Walmsley, J. (2011). An investigation into the implementation of annual health checks for people with intellectual disabilities. *Journal of Intellectual Disabilities, 15*(3), 157–166. http://dx.doi.org/10.1177/1744629511423722

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures* [Electronic version]. Retrieved from https://www.amazon.com/Inclusive-Research-People-Learning-Disabilities/dp/1843100614

Walumbwa, F., Avolio, B. J., Gardner, W. L., Wernsing, T. S., & Peterson, S. J. (2008). Authentic leadership: Development and validation of a theory-based measure. *Journal of Management*, *34*(1), 88–126.

Wetherow, D. (n.d.). *The star raft process*. Retrieved from http://thestarraft.com/the-star-raft-process/

World Health Organization. (2011). *World health: Disability and rehabilitation*. Retrieved from http://www.who.int/disabilities/world_report/2011/report/en/

Worrell, B. (1988). *People first: Advice for advisors.* Downsview, Canada: National People First Project.

Yuker, H. E. (1970). *The measurement of attitudes toward disabled persons*. Retrieved from http://files.eric.ed.gov/fulltext/ED044853.pdf

"A revolution that is based on the people exercising their creativity in the midst of devastation is one of the great historical contributions of humankind." — Grace Lee Boggs

Chapter 2:

Ongoing Voices of Isolation and Marginalization of People with Intellectual Disabilities Supported in different Kinds of Programs: The “Cocoon of Impossibility”

Aaron Johannes, Ginny Belden-Charles, & Jasmina Serminj

Abstract

This article examines how different kinds of narratives have shared similar language, images, and concepts of segregation as they have been voiced by people with intellectual disabilities throughout a half-century of support models that have been posited as radically different. Although support ideologies have moved from institutionalization to segregation to community inclusion, the stories of people with intellectual disabilities have shared overlapping perspectives on how segregation has continued to be experienced and are hauntingly the same. Further, there is evidence that these voices have seldom been attended to, as hard-won published stories and autobiographies, and the documents of inclusive research have rarely been used as primary sources.

Relationship of this Article to the Dissertation

This dissertation's primary research question examines what has worked to support people with ID as leaders in their lives, groups and communities. From the beginning of our discussions self-advocate advisors to the research wanted to focus on "stories of successful and satisfying leadership experiences." Two concurrent pathways came out of this directive. First, the recording of stories as data in community conversations. Second, the acquisition of self-advocate stories and their addition to the literature review for this research. These were in the form of biographies that had been written by them or with support, with further, unsuccessful searches to find similar stories by younger self-advocates who had not experienced institutionalization. Instead their stories were found within other documents related to board development, research and government projects. This led to a consideration of the ways that self-advocates were able to access opportunities to tell their stories, resulting in this article. The article compares different kinds of stories – autobiographical and interstitial – as a way to examine self-advocate access to what they consider one of their strongest leadership tools. Thus, in terms of the question of what works for self-advocate leaders, stories "work" to support them. However, there are also implications in that their stories are not heard, or not attended to by various parties, and that although they are

posited as having increased access to community they appear to have less access to telling their "untamed" stories.

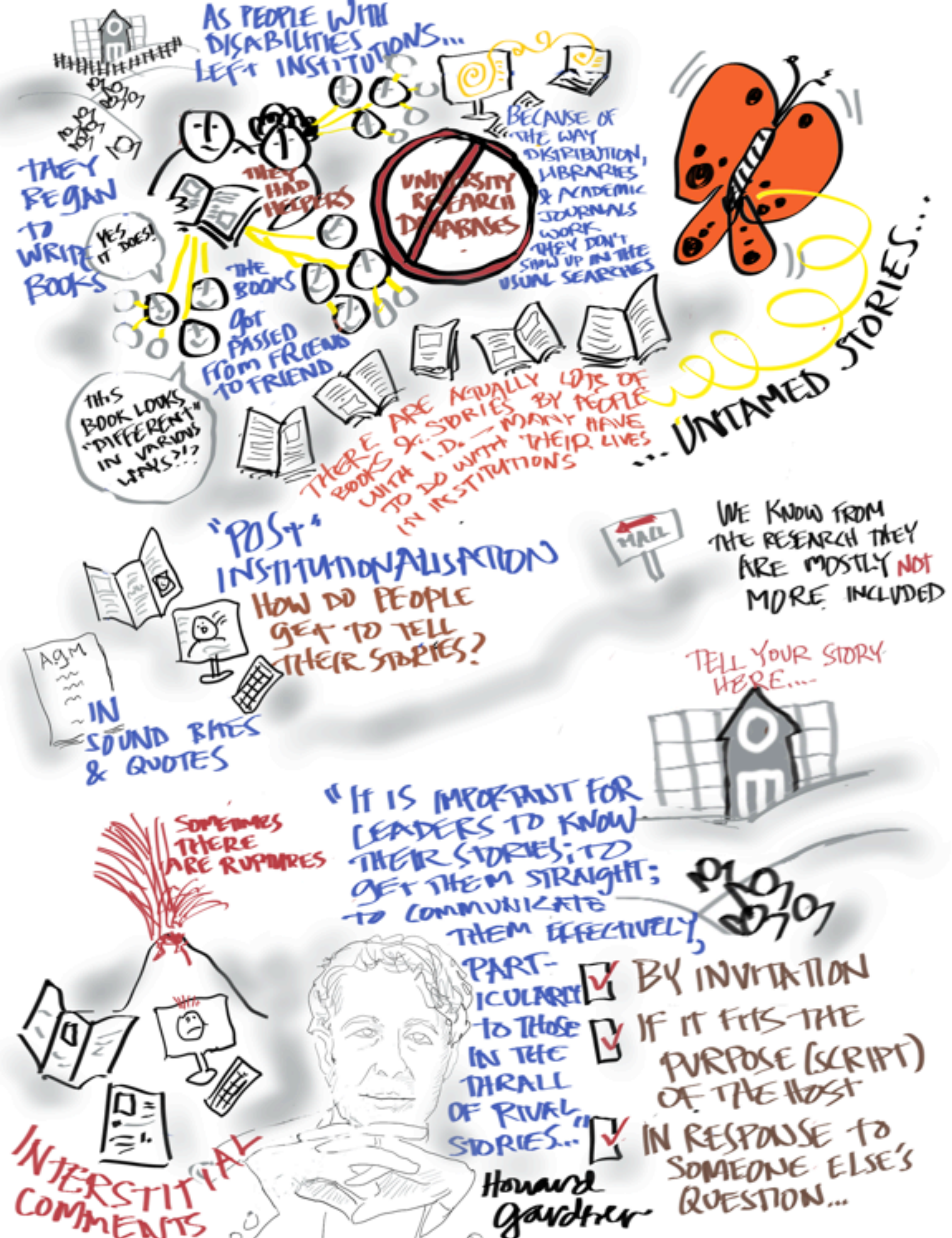


Figure 7. Graphic rendering of this paper for discussion with people with disabilities.

Publishing History

Published: Research and Practice in Intellectual and Developmental Disabilities

ISSN: 2329-7018 (Print) 2329-7026 (Online)

Journal homepage: http://www.tandfonline.com/loi/rpid20

DOI: 10.1080/23297018.2017.1309986

Published online: 05 Jun 2017. Accepted 14 January 2017

Citing articles [as of June 10, 2017]: 2

Introduction

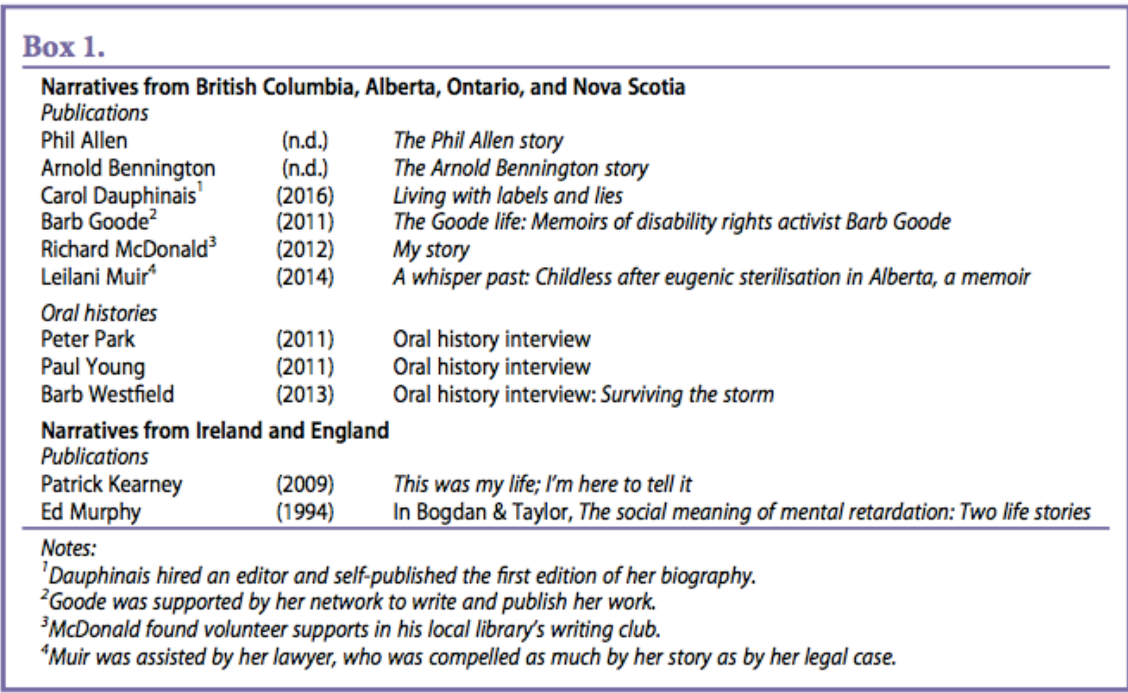
The concept of social inclusion is a central platform in policies aimed at creating a better and more meaningful life for people with intellectual disabilities. Yet the literature is replete with conclusions that suggest achieving social inclusion has been problematic to say the least (Amado, Stancliffe, McCarron, & McCallion, 2013; Ben-Moshe, 2011; Cummins & Lau, 2003; Verdonschot, De Witte, Reichrath, Buntin, & Curfs, 2009). This article analyzes examples of self-advocate narratives over the last 50 years by people who have been labelled as having intellectual disabilities. It compares stories of institutionalization to stories of life in contemporary community settings. In doing so, it seeks to amplify the voices of those people with intellectual disabilities who have experienced changing support models and consider whether they now believe themselves to be more included than previously. We examine the theme of segregation, how it is felt, and how it is expressed in the telling of these disparate stories. A difference was intuited between earlier post-institutional stories and more contemporary stories. This raised questions, such as who was able, or invited, to tell their stories; who facilitated such invitations; and under what conditions were such stories disseminated?

The shift of our cultural ideal from segregation to inclusion implies an increase in community access and empowerment. Moreover, given the association of empowerment and inclusion with the idea of "voice," the ways in which voices are facilitated or suppressed are important sociocultural indicators of the actual relations of power. Yet until quite recently, the voices of people with intellectual disabilities have been largely unacknowledged in evaluation of policies aimed at achieving social inclusion. By analyzing the emergent problems of social inclusion through the lens of self-advocate narratives, we can begin a critical examination of the programmatic changes associated with the move from institutional models towards inclusion-focused community programs. The self-advocate narratives analyzed in this article reflect the social realities experienced by people with intellectual disabilities. They also

demonstrate the degree to which, despite seismic policy shifts, some historical hierarchical subject-object power relations remain effectively unchanged.

Self-advocate autobiographies.

This article examines two kinds of story. The first consists of the stories of self-advocate autobiographical writers about institutional events that ended in British Columbia, Canada, with the closure of the last institution in 1996. This first group of stories is mainly comprised of local publications. It seems that all over the world there have been similar representative books and stories by self-advocates and most of these have had a limited distribution. They are, however, hard to locate through searches of formal academic databases. Consequently, the relational networks of the authors were used to invite people with intellectual disabilities to provide information about "autobiographical" works of which they were aware, and copies of these were obtained through a similar means. The stories of institutional and/or segregated lives collected were each written, or spoken and scribed, by a person with an intellectual disability who had then controlled its publication and dissemination.



Box 1.

Narratives from British Columbia, Alberta, Ontario, and Nova Scotia		
Publications		
Phil Allen	(n.d.)	*The Phil Allen story*
Arnold Bennington	(n.d.)	*The Arnold Bennington story*
Carol Dauphinais[1]	(2016)	*Living with labels and lies*
Barb Goode[2]	(2011)	*The Goode life: Memoirs of disability rights activist Barb Goode*
Richard McDonald[3]	(2012)	*My story*
Leilani Muir[4]	(2014)	*A whisper past: Childless after eugenic sterilisation in Alberta, a memoir*
Oral histories		
Peter Park	(2011)	Oral history interview
Paul Young	(2011)	Oral history interview
Barb Westfield	(2013)	Oral history interview: *Surviving the storm*
Narratives from Ireland and England		
Publications		
Patrick Kearney	(2009)	*This was my life; I'm here to tell it*
Ed Murphy	(1994)	In Bogdan & Taylor, *The social meaning of mental retardation: Two life stories*

Notes:
[1]Dauphinais hired an editor and self-published the first edition of her biography.
[2]Goode was supported by her network to write and publish her work.
[3]McDonald found volunteer supports in his local library's writing club.
[4]Muir was assisted by her lawyer, who was compelled as much by her story as by her legal case.

Figure 8. Summarizes the autobiographical narratives reviewed.

As people with intellectual disabilities left institutions, they aspired to control their own stories as a way of controlling their own lives. This required finding pathways to enable their autonomy as writers. None of self-advocate books reviewed were published in partnership with the agencies supporting those individuals. Rather, self-advocates found support outside the service system to write and publish their own works. In these narratives, who arrives to assist with their production matters more than other factors such as the ability to write, edit, produce, and publish a manuscript. Adopting a critical approach to documenting and investigating the history of institutional care remained an important motivation for each storyteller as well as his or her allies.

The books of self-advocates are often ephemeral and not based on a typical understanding of what a book might be. The late Arnold Bennington was one of the earliest self-advocate leaders to conceive of, write, and create a book about his post-institutional life. He did not differentiate between "publishing" and "printing" his work, nor was the idea of editions all that meaningful to him. Working independently and using simple desktop publishing programs, his iterations changed unapologetically, and each iteration was "published" depending on his budget and his printer. Distribution was an ad hoc process that occurred when Bennington presented copies of his story to those he felt had made a significant contribution to the self-advocate community. While the title of Bennington's story remained the same across every edition, the content of his story could, and often did, change from one edition to the next. For example, early editions focused on Bennington's self-advocacy career and emancipation. By contrast, the last "edition" combined some of that story with a more contemporary story of meeting and reuniting with his lost birth family. This latter story interspersed with photographs of his newly met relations, old copies of what he identified as "suspect" institutional and government documents, and his own plain language commentary (Bennington, n.d.). This porousness in Bennington's story is reminiscent of the seemingly random recipes that appear in Goode's (2011) autobiography of her career as an important global self-advocate. For Goode, the recipes represented the voices of her

family's belief that she was literate, could read the recipes, and thus live on her own and cook. In reliving their stories, most authors had undergone considerable trauma, as illustrated by Dauphinais (2016), who wrote,

> *Over the 18 months it took me to write – and I wrote longhand – I changed. I think I was possessed while I was writing it. If I was working a late shift, I got out of bed at 3:30 a.m. and wrote until 9:30 a.m. I got so I couldn't sleep. I was reliving it all. I was there. I was having nightmares, the same ones I had when I was little. . . . I hadn't realised how much I had endured as a child. I became a nervous wreck, but I couldn't stop. What kept me going? . . . I knew it had a happy ending.* (p. 122)

As with other authors, Dauphinais (2016) was motivated to share her story with the stated intention of ending segregation, isolation, and its associated abuses: "I offer my story on behalf of all children," she wrote, "who've been abused by people who should have been protecting them" (p. 21).

Stories about the lives of people with intellectual disabilities who had lived in institutions have continued to grow and been fundamental to their developing emancipation (Sobsey, 2001). Dorothy Atkinson (2010) maintained that autobiographical life stories convey identity and experiences. Meanwhile, the self-advocate Mabel Cooper (as cited in Atkinson, 2010) stated that life stories can give you "something to show for your life . . . so that you can say, 'That's what happened to me'" (pp. 7–8). These narratives have, for the most part, been voluntary offerings, and often the initial offering was to the person's network, which responded with a belief that the story should be shared more widely. Yet they rarely appear in databases used in academic research, nor in library collections. The reasons for this are varied but include differing notions of what a book might be, or an author's lack of access to formal publishing and distribution systems. Dauphinais's (2016) own frustration with this barrier to dissemination motivated her to buy and donate copies of her book to every library in British Columbia.

Post-deinstitutionalization fragmented narratives of self-advocates.

The time frames of autobiographical books written by previously institutionalized people ended as community inclusion became a primary focus of policy

and government-funded programs. A similar body of contemporary, autobiographical self-directed self-advocate narratives by people with intellectual disabilities supported in inclusion programs was harder to identify. Thus, the second type of stories were rather more complex. We drew on other sources of self-advocate commentary for inferential evidence about contemporary community isolation/exclusion. Our main sources were more interstitial stories; that is to say, self-advocate stories documented in interviews and other written forms. The stories in the second group are self-advocate commentaries and fragments of their voices included in articles published in journals drawn from interviews, and participatory research projects. Of particular interest were stories from “inclusive schools” or “community inclusion” programs, in which participants are purportedly supported to access community. For example, self-advocates narratives found in research about “community inclusion” programs (e.g., Ford, 2012), inclusive research texts (Walmsley & Johnson, 2003), ethnographies (e.g., Finn, as cited in Caldwell’s [2010] collection of self-advocate leaders’ narratives), and government-hosted sites (e.g., Paul Baldwin’s [n.d.], “My Journey,” a guest blog on the British Columbia provincial self-advocacy information site). These texts often make interstitial statements (as in Baldwin’s story) about governments’ commitment to inclusion. Baldwin (n.d.), for example, tells the story of how hard he has had to advocate to have the government follow through on this commitment: “I got little supports, but they were always extremely supportive” (para. 2). Jerry Laidlaw’s biography of the Board of Directors of the Self-Advocacy Caucus, provides a further example of such conflicting statements. The biography moves abruptly from outlining some of Laidlaw’s (n.d.) accomplishments to drawing attention to ongoing experiences of segregation. Laidlaw (n.d.) wrote, “I have a passion for life and learning. I continue to advance my education and . . . am an active volunteer in my community” (para. 1), and then noted, “I know first-hand the isolation that many self-advocates experience” (para. 1). This type of first-hand statement about isolation and segregation published as part of broader texts represents a rupture of voice and intrudes upon a narrative that was ostensibly written to commend that service organization. Such jarring statements of

marginalization remind us that isolation remains a problem even in some organizations committed to social inclusion.

Together, these two types of stories form a self-advocate narrative about ongoing exclusion and inclusion. This article is concerned with the reoccurring themes prevalent throughout these two bodies of work. The concepts underpinning institutionalization – such as care and control – have been posited as radically different to those underpinning the concept of community living – such as human rights and social inclusion. Yet in each group of stories the language, images, and conceptualization of segregation remain hauntingly the same.

Institutional stories.

The literature from the era of overt segregation encompasses a variety of texts, including autobiographies, monographs, and biographical anthologies about life in institutions and segregated environments. Analysis of these narratives focused on statements about how segregation had been executed and how it felt at the time and later. The objections were clearly illustrated by Leilani Muir (2014), who described carefully deployed degrees of segregation as punishment for non-compliance. Muir recalled being placed in an institution and then moved from her “home” ward to an isolation cell and, as further punishment, to a ward for what were called “lower functioning” people: “We girls called them the ‘punishment wards’” (p. 42) and there was “a tiny window . . . the matrons could see in but I could not see out” (p. 42). Similarly, Phil Allen (n.d.) wrote that during government inspections, “[we were to say that] everything was just fine. If we dared . . . try to tell the truth we were locked in little side rooms as punishment and left there” (p. 11). McDonald and Bax (2012) wrote that telling tales “out of school” about what was going on in the institution was punished by wearing a label that said, “LOP [loss of privileges]” (p. 1) for 2 weeks. A loss of privileges included privations such a pushing a block and polishing rag over the linoleum, eating bread and water in isolation, and a suspension of visiting rights for all family members (McDonald & Bax, 2012, p. 1). Canadian self-advocate leader Peter Park (Park & McDonagh, 2011) described his experience of institutional life in terms of lost years:

"I'm fifty-nine . . . take 18 years off that, and that's my right age. . . . That's the way I look at it, I'm only forty-one" (p. 82). When Ed Murphy (1994) joined some 4,000 residents at Empire State School, he found, "Retarded persons are . . . exiled from society" (p. 41). Murphy drew unflattering comparisons between institutions and prisons but suggested one significant difference: in an institution "you don't know what is going on, why you are there or for how long" (p. 41). The implication Murphy made was that at least the prisoner knows why s/he is there and also that s/he has a date penciled in for prospective release (pp. 41–42).

These historical case studies demonstrate that what is being objected to is, not least, isolation perceived as unreasonable and enacted as punishment. The autobiographical writings themselves are evidence of change and indicate that self-advocates have found their voice and are free to tell what have been called "untamed" stories (Sermijn, Devlieger, & Loots, 2008).

Narratives from the era of community inclusion.

While the first genre of self-advocate narratives is full autobiographies about lives lived under the program of segregation, the second type of narrative occurs within programs of inclusion. Certainly, it is more difficult and complicated to declare oneself a "survivor" of a "community inclusion" program. Clear self-advocate commentaries have been replaced by a more collegial rhetoric in which there are fewer opportunities for critical reflection and self-advocacy assertiveness by those experiencing community-based support. A possibility might be that this gap indicates satisfaction with "community inclusion" programs.

However, there is evidence that suggests little has actually changed and that the isolation earlier self-advocates objected to continues to exist, or is addressed in only tokenistic ways. As one government funder said, "Loading people on the bus and taking them to Tim Hortons [coffee shop] at 2 p.m. in the afternoon is not community inclusion" (Komarnicki, 2013, para. 5).

Interstitial quotes from self-advocates point out the continuing problem of segregation and how it feels. One graduate of an inclusive school later stated in a focus group on another subject:

> *I was always in the special needs program I never, ever, ever got to go to class with any of the other peers . . . and . . . the worst thing I remember about it is . . . people stare at me and laugh their asses off because you know . . . they knew they never saw me in any other classes. . . . You know, that kind of stuff kills a person.* (Ford, 2012, p. 14)

Similarly, six focus groups that discussed housing in different geographical locations each identified isolation as a theme. Examples of participants' comments were: "I miss where I used to live, the countryside, local shops and old neighbours. I miss my old friends"; "I had better neighbours where I used to live"; "All my good neighbours have moved to other houses in different places, but I can't afford to move"; and "I have had to move from home, people aren't very helpful, not like my old neighbours and they don't speak to you in the street" (Barr, McConkey, & McConaghie, 2003, p. 588). It is impossible to know from these statements why individuals moved. However, as was the case in British Columbia, it is probable that these moves were positioned as attempts to increase inclusion or independence and occurred through changes in program models or in service delivery. At least one participant stated, "I have had to move."

Self-advocate Chester Finn (2007), after spending his entire life in the community, was placed in a day program to recover from an illness. Finn found that the program's guidelines for ensuring his safety were, in practice, rules that could foster isolation and disempowerment:

> *You know, they [his neighbours] get to know who I am, or they get to know who my friends are. . . . They're going to look at the things that I like. They're going to go to the places that I like. See the people, meet the people that I know. Because that way, you're educating your community, and you're educating people. . . . And you can't teach people, if you're not there. . . . If they don't see you, they don't know that you can do things.* (p. 58)

A strong self-advocate with a powerful network, Finn (2007) was nevertheless challenged to extricate himself from programmatic services that were isolating once they had been put in place.

Researching inclusion.

During an early deinstitutionalization project that introduced people to their communities, one child remarked:

> *We were learning about a new thing completely. . . . Not like . . . Shakespeare, because we'd heard about him! We were learning about new people, that they were among us all the time, and they were just around the corner going to this Adult Care Unit, which none of us had heard of before.* (McConkey & McCormack, 1984, p. 113)

Fourteen years later, the authors of an article titled "Outside Looking In? Studies of the Community Integration of People with Learning Disabilities" found that people with intellectual disabilities "live within geographically defined communities, and use local facilities and resources" (Myers, Ager, Kerr, & Myles, 1998, p. 404), yet are often unknown and isolated. Fifteen years later, one of the most thorough meta-studies of inclusion research concluded: "society has done a better job of increasing the community presence of people with an ID [intellectual disability] than in facilitating their 'living' within the community" (Amado et al., 2013, p. 362).

Taxonomies of segregation.

One criticism of research focused on community inclusion is that the concept of "community" is rarely clearly defined (Verdonschot et al., 2009). However, in self-advocate narratives, segregation and marginalization – the conceptual opposites of inclusion – are described as a careful, purposefully imposed, iterative, and incremental process in both institutions and "community inclusion" programs. In many self-advocate stories, isolation equals punishment, as people are further isolated within institutions as a response to their differences or as a result of their actions or their objections to their treatment. Early self-advocate authors almost invariably stated that their motivation to share these stories was to make sure similar events would not happen again. Yet, hauntingly, contemporary segregation of school children for perceived infractions have

been similarly described. A recent survey on the practices of restraint and seclusion in inclusive schools in British Columbia began with a clarification of the language of "seclusion":

> *Seclusion: Placement in an isolated area for an extended time and prevention from leaving the area. Example: Placing an individual in a locked room or closet, or where a person of authority blocks exiting this room.*
>
> *Other terms used may include: isolation time out alone time quiet time taking a break sensory break exclusion personal office time.* (Inclusion BC & Family Support Institute of BC, 2013, p. 1)

As in the documents of earlier times, it is clear that segregation and isolation has continued as a somewhat organized strategy of distancing from peers, supervising adults, environments, and potential community experiences as the result of perceived objectionable behaviours. The report stated that 84% of children who responded to the survey reported that they were "physically prevented" (Inclusion BC & Family Support Institute of BC, 2013, p. 8) from participating and kept in segregated spaces. More specifically, they were "sent out alone, unsupervised for others to see and feel full humiliation" (Inclusion BC & Family Support Institute of BC, 2013, p. 8); "not permitted to go . . . to a weekly out of school dance class" (p. 8); placed in resource rooms, "surrounded on all sides by furniture" (p. 8); placed with other children with intellectual disabilities; kept at the back of the class in a corner; and in one case had a "cardboard carrel built around him" (p. 8). Documented responses of children to segregation ranged from self-injurious behaviours to anxiety, school aversion, ostracization by peers, and feeling like "strangers" during rites of passage such as graduation ceremonies.

Differentiation as exile.

Early self-advocates expressed the view that isolation and assumptions about their incompetence served to reinforce the feelings of powerlessness embedded in the process of segregation. A legacy sculpture on the former grounds of British Columbia's largest institution, designed by Richard McDonald in 2012, featured high window frames to replicate those windows that had denied the residents' a view of the outside world, while also denying the community an opportunity to witness the "abuse that was going

on inside" (McDonald & Bax, 2012, p. 9). Both Dauphinais (2016) and Muir (2014) wrote about situations in which they were seen, but were unable to see their observers, and thus raised the spectre of panopticon-like power imbalance (Brunon-Ernst, 2007). Similarly, a startling photograph in the Inclusion BC and Family Support Institute of BC's (2013) contemporary *Stop Hurting Kids* report showed a seclusion room in an inclusive school that had a window through which children could be observed (p. 5).

People with intellectual disabilities have occupied diverse arrangements in society, ranging from segregated institutions to segregated relations within integrated programs, to community inclusion programs, to actual inclusion in community life. In government documents such options have often been perceived as equal, if different. The charged term of "exile" (societal punishments for criminality beyond redemption, or political states of being in opposition to the government) seemed only to run through earlier, experiential self-advocate narratives. In later narratives, from the various kinds of community inclusion opportunities now available to people with intellectual disabilities, it was more difficult for people to state their feelings. However, some moments of rare clarity can be found in the literature, such as when Thomas F. Allen, Traustadottir, and Spina finally moved from an institution to his own apartment: "[It] did not bring me the freedom I had dreamed "about," explained Allen, because what he did, when, where, and with whom continued to be controlled and monitored by staff. The ongoing scrutiny of his life left Allen feeling "still quite isolated" (T. F.Allen, Traustadottir, & Spina, 2005, p. 161). This subtle realization that isolation is not merely a physical state of being distanced, but also one of being controlled and monitored, slipped into Allen et al.'s story.

Interstitial ruptures.

Post-institutionalization, a more gentle form of exile continues. Paul Young (Young & McDonagh, 2011), a People First leader who never lived in an institution and had what contemporary self-advocates term as "real work for real pay" all his life, spoke of his peers as snared within "the cocoon of impossibility" (p. 42). By this he meant shut away in "sheltered, segregated classes, workshops, the traditional services that people

with intellectual disabilities receive" (p. 42). The constructed othering of people with intellectual disabilities as "cognitive foreigners" (Bach, 2015, 4:11) was also evident when program participant Marie said of her community inclusion day supports: "It is a community, but it's a closed community. We are all closed in to one big room" (Milner & Kelly, 2009, p. 54). This statement is radically different from Ed Murphy's (1994) suggestion that "retarded persons are . . . exiled from society" (pp. 41–42). Even so, when researchers invited Marie to coffee, she disclosed that she had never been to the local coffee shop. She had only been to the mall with staff, who had taken her along as part of a larger group. "I guess I know the outside of Invercargill," Marie explained, "but not much of the inside" (Milner & Kelly, 2009, p. 47).

As people with intellectual disabilities recognize the subtle ways in which they are segregated and marginalized in contemporary services, the challenges of agency and voice are expressed as "feelings" through intermittent, interstitial ruptures, or embedded as fragments within other narratives. As a strategy for creating space for voice and agency, ruptures of voice become both pattern and theme. For example, people who have moved homes, as in the example above, find a way to comment on their increased isolation as well as their housing. The difficulty is finding pathways to resolve their concerns. If one is placed in a program or housing that theoretically supports inclusion, it is hard to know what to object to, or to whom. This may be the result of changing terms for new kinds of segregated experiences. As one participant in a focus group for a program review stated, "You know how they are trying to put money into all these programs trying to make them fancy, and fancy names and this and that . . . what kids really need, is relationships with other peers their age" (Ford, 2012, p. 15).

Common Stories and Themes

While contemporary programs to support inclusion are situated as notably and intentionally different from institutional and segregated programs, the language, imagery, and feelings used by participants to describe such programs are hauntingly similar to descriptions of institutional segregation. Contemporary self-advocate voices provide more subtle clues about isolation than the photo of an individual alone in a

room. In both kinds of story people are stigmatized and distanced from typical social interactions through active management of their environment, the times of activities, or staff supports.

Furthermore, in both kinds of story participants do not choose their own activities; they are grouped without consent, usually with others with shared deficits; and they are offered no other choices. As in institutions, there is no opportunity for people with intellectual disability to voice their concerns or have agency over themselves and their identities in community programs. However, the language of contemporary inclusive programs is often twisted and contorted and thus more difficult to challenge. Even so, self-advocate voices suggest that exclusion, isolation, and marginalization continue to exist in some programs. While some people with intellectual disabilities have become autonomous, powerful leaders in their lives, their groups, and their communities, others had no choice where they went, with whom, or how they were treated.

Autonomously written life stories – which, as we have shown, might also be called "untamed" stories – offer the authors an opportunity to construct their own identity and that of their culture (Sermijn et al., 2008). The stories that focus on institutional supports often intersect with broader historical themes and can, to some extent, represent "the history of many thousands of people who . . . were labelled and excluded from everyday life . . . [and] lived to a large extent in a separate world" (Atkinson, 2010, p. 8). Such accounts are "necessary to the construction of an emancipatory disability history" (Malacrida, 2005, pp. 523–524). Yet the opportunities to create and control such narratives about contemporary inclusive programs appear to have diminished rather than expanded. If exclusion continues without an articulate, recognizable self-advocate commentary, more subtle experiences of segregation are more difficult to grasp and object to. While people with intellectual disabilities are nominally part of their communities, their identities and agency require regular negotiation and self-advocacy, and it is possible that inclusion that is programmatic rather than open-ended and authentic has served more to suppress dissent and support

a collegial commentary. This raises a critical point about such narratives. Though framed within the context of "inclusion," why do contemporary self-advocate narratives continue to present themes associated with marginalization? Moreover, why are there so few contemporary narratives and why is fragmentation in such narratives a problem? It would seem that the decrease in, and fragmentation of, these narratives is not due to the disinterest of the people with intellectual disabilities themselves. The leaders of the British Columbia People First, a self-advocacy organization in Canada, made that much clear when they included, in a short list of what they were most proud of, the statement "We have our own books now" (Johannes, 2012, p. 1).

Finally, it is significant that even "suitable" narratives, created with the support of caring others, remain outside academic searches and literature reviews. The depth of this absence-making is a reflection of power relations. This brief exploration of the narratives of people with intellectual disabilities and their lived experiences of exclusion and marginalization has provided glimpses into what might be referred to as a socially constructed absence.

Conclusions and Suggestions for Further Research

This article compared secondary, written sources of self-advocates' narratives with earlier autobiographic sources from a small geographic area. While the experiences and narratives appear consistent with those from other areas, a larger and more rigorous body of research is necessary to more fully understand the dynamics of self-advocate voices over generations, within different service paradigms.

Research that demonstrates similar findings without evidence of compelling significant change might be, as Gergen (2015) says, "future forming" (p. 1). Further, facilitated, open-ended dialogues with people with intellectual disabilities about their lived experiences, and the feelings of inclusion and marginalization they experience, would yield a useful new body of information. In Europe, a great deal of good work explored the potential for inclusive research to support the exploration of self-advocate interests and help them gain voice (Walmsley & Johnson, 2003). Meanwhile, in the United States, co-researchers with intellectual disabilities have experimented with

dyadic interviewing (Caldwell, 2013) and in Canada with technology supported collaborative research (Davidson, 2012). Continued investigation of how authors with intellectual disabilities who have written their own books, and what they wished to achieve from doing so, would be a useful addition to the literature and welcomed by the self-advocate community.

References

Allen, P. (n.d.). *The Phil Allen story*. Vancouver, BC: PLAN (Planned Lifetime Advocacy Network).

Allen, T. F., Traustadottir, W. R., & Spina, L. (2005). It's never too late. In K. Johnson & R. Traustadottir (Eds.), *Deinstitutionalization and people with intellectual disabilities: In and out of institutions* (pp. 157–162). London, United Kingdom: Jessica Kingsley.

Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities*, *51*(5), 360–375. doi:10.1352/1934-9556-51.5.360

Atkinson, D. (2010). Narratives and people with learning disabilities. In G. Grant, P. Ramcharan, & M. Flynn (Eds.), *Learning disability: A life cycle approach* (pp. 7–27). New York, NY: Open University Press.

Bach, M. (2015, October 30). Closing conference reflections, centre for inclusion and citizenship rights based social policy [Video file]. Retrieved from https://www.youtube.com/watch?v=DEg6UY0T_aE

Baldwin, P. (n.d.). *My journey*. Retrieved from http://selfadvocatenet.com/my-journey/

Barr, O., McConkey, R., & McConaghie, J. (2003). Views of people with learning difficulties about current and future accommodation: The use of focus groups to promote discussion. *Disability & Society, 18,* 577–597. doi:10.1080/0968759032000097834

Ben-Moshe, L. (2011). The contested meaning of "community" in discourses of deinstitutionalization and community living in the field of developmental disability [Electronic version]. *Disability and Community* (Vol. 6, pp. 241–264). doi:10.1108/S1479-3547(2011)0000006013

Bennington, A. (n.d.). *The Arnold Bennington story*. Unpublished manuscript.

Brunon-Ernst, A. (2007). Foucault revisited. *Journal of Bentham Studies, 9,* 1–10.

Caldwell, J. (2010). *Leaders with developmental disabilities in the self-advocacy movement*. Retrieved from http://bancroft.berkeley.edu/ROHO/collections/subjectarea/ics_movements/self_advocacy.html

Caldwell, K. (2013). Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research, 14*(4), 488–507. doi:10.1177/1468794113490718

Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 16*(2), 145–157. doi:10.1046/j.1468-3148.2003.00157.x

Dauphinais, C. (2016). *Living with labels and lies* (2nd ed.). Vancouver, BC: Spectrum Press.

Davidson, A.-L. (2012). Use of mobile technologies by young adults living with an intellectual disability: A collaborative action research study. *Journal on Developmental Disability, 18*(3), 21–32.

Finn, C. (2007). *Oral history usage guidelines*. Retrieved from http://digitalassets.lib.berkeley.edu/roho/ucb/text/finn_chester.pdf

Ford, F. (2012). *Self-advocate engagement: Individuals' perspectives on services and supports for people with developmental disabilities*. Victoria, Canada: Ministry of Social Development.

Gergen, K. J. (2015). From mirroring to world-making: Research as future forming. *Journal for the Theory of Social Behaviour, 45*(3), 287–310. doi:10.1111/jtsb.12075

Goode, B. (2011). *The Goode life: Memoirs of disability rights activist Barb Goode.* Vancouver, Canada: Spectrum Press.

Inclusion BC & Family Support Institute of BC. (2013). *Stop hurting kids: Restraint and seclusion in BC schools – survey results and recommendations*. Retrieved from http://www.inclusionbc.org/sites/default/files/StopHurtingKids-Report.pdf

Johannes, A. (2012). *Photos: Graphic recording, celebrating achievements and imagining possibilities, B.C*. Retrieved from https://bcpeoplefirst.wordpress.com/#jp-carousel-139

Komarnicki, J. (2013, March 29). Disabled support program slashed because it wasn't working, says province. *Calgary Herald.* Retrieved from http://www.calgaryherald.com/disabled+support+pro gram+slashed+because +wasn+working+says+province/8170682/story.html

Laidlaw, J. (n.d.). *Inclusion BC board of directors*. Retrieved from http://www.inclusionbc.org/about-us/how-we-work/board-directors/jerry-laidlaw

Malacrida, C. (2005). Discipline and dehumanization in a total institution: Institutional survivors' descriptions of time-out rooms. *Disability & Society, 20*(5)*,* 523–537. doi:10.1080/09687590500156238

McConkey, R., & McCormack, B. (1984). Changing attitudes to people who are disabled: A review of research and implications for mental handicap. *Journal of the British Institute of Mental Handicap, 12*(3)*,* 112–114. doi:10.1111/j.1468-3156.1984.tb00231.x

McDonald, R., & Bax, H. R. (2012). *My story.* New Westminster, BC: Royal City Writers.

Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society, 24*(1)*,* 47–62. doi:10.1080/09687590802535410

Muir, L. (2014). *A whisper past: Childless after eugenic sterilisation in Alberta.* Victoria, Canada: Friesen Press.

Murphy, E. (1994). Ed Murphy's story. In R. Bogdan & S. J. Taylor (Eds.), *The social meaning of mental retardation: Two life stories.* New York, NY: Teachers College.

Myers, F., Ager, A., Kerr, P., & Myles, S. (1998). Outside looking in? Studies of the community integration of people with learning disabilities. *Disability & Society, 13*(3), 389–413. doi:10.1080/ 09687599826704

Park, P., & McDonagh, P. (2011). In A. Johannes, S. Stanfield, J. Reynolds, & P. McDonagh (Eds.), *From institutions to individuals* (pp. 85–92). Vancouver, Canada: Spectrum Press.

Sermijn, J., Devlieger, P., & Loots, G. (2008). The narrative construction of the self: Selfhood as a rhizomatic story. *Qualitative Inquiry, 14*(4), 632–650. doi:10.1177/1077800408314356

Sobsey, D. (2001). Dale Evans and the great rescue: A parent's view. *Mental Retardation, 39*(5), 401–404. doi:10.1352/0047-6765(2001)039<0401:DEATGR >2.0.CO;2

Verdonschot, M. M. L., De Witte, L. P., Reichrath, E., Buntin, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research, 53*(4), 303–318. doi:10.1111/j.1365-2788.2008.01144.x

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures.* Philadelphia, PA: Jessica Kingsley.

Young, P., & McDonagh, P. (2011). In A. Johannes, S. Stanfield, J. Reynolds, & P. McDonagh (Eds.), *From institutions to individuals* (pp. 41–48). Vancouver, Canada: Spectrum Press.

There are two ways of telling your story. One is to tell it compulsively and urgently, keep returning to it because you see your present suffering as the result of your past experiences. But there is another way. You can tell your story from the place where it no longer dominates you. You can speak about it with a certain distance and see it as the way to your present freedom. — Henri Nouwen

Chapter 3:

Sensemaking to Support Leadership through Arts-Infused Planning Processes for People with Intellectual Disabilities and Inclusive Groups

Abstract

Person-centred planning processes are considered best practice in supports for people with intellectual disabilities. This article uses PATH as an exemplary method to examine the thinking behind the process, and then demonstrates how simple, related processes might be used to better involve people with ID in community development. To this end, we examine the invitational aspect of PATH and how people can expand and activate their networks by looking at some stories of planning that incorporate arts and the performative. We build on these ideas with a discussion of how related ideas were used in larger groups of people with and without disabilities to create conditions for more informed, systemic change. Finally, ideas for expanding these facilitation practices in local environments are given.

Relationship of this Article to the Dissertation

People with ID saw leadership as a meaningful issue in their lives, groups, and communities. They wanted more clarity and welcomed the idea of an exploration of what leadership was for them, and how it might differ from traditional expectations, so that they could leverage their capacity in different contexts. This led to the research question of this dissertation: for people with ID, what works to support them in leadership in their lives, groups and communities? The PATH process, as an exemplary form of person-centred planning, has been successfully used for some 30 years to help people plan for their goals and supports, and is considered a best practice methodology to support people to lead their lives by identifying their goals and planning ways to work towards them. This paper examines this process and the extrapolation of some aspects of that person-centred planning process and how these have been used in more broadly inclusive facilitation methods. It does so by telling stories of planning events that focused on people and networks as well as of larger dialogic events that also included graphic recording to promote self-advocate leadership in community development. In effect it answers the more practical aspect of this overall research, which has to do with what methods might be used to involve people with ID in leadership of various kinds, by documenting some possible methods.

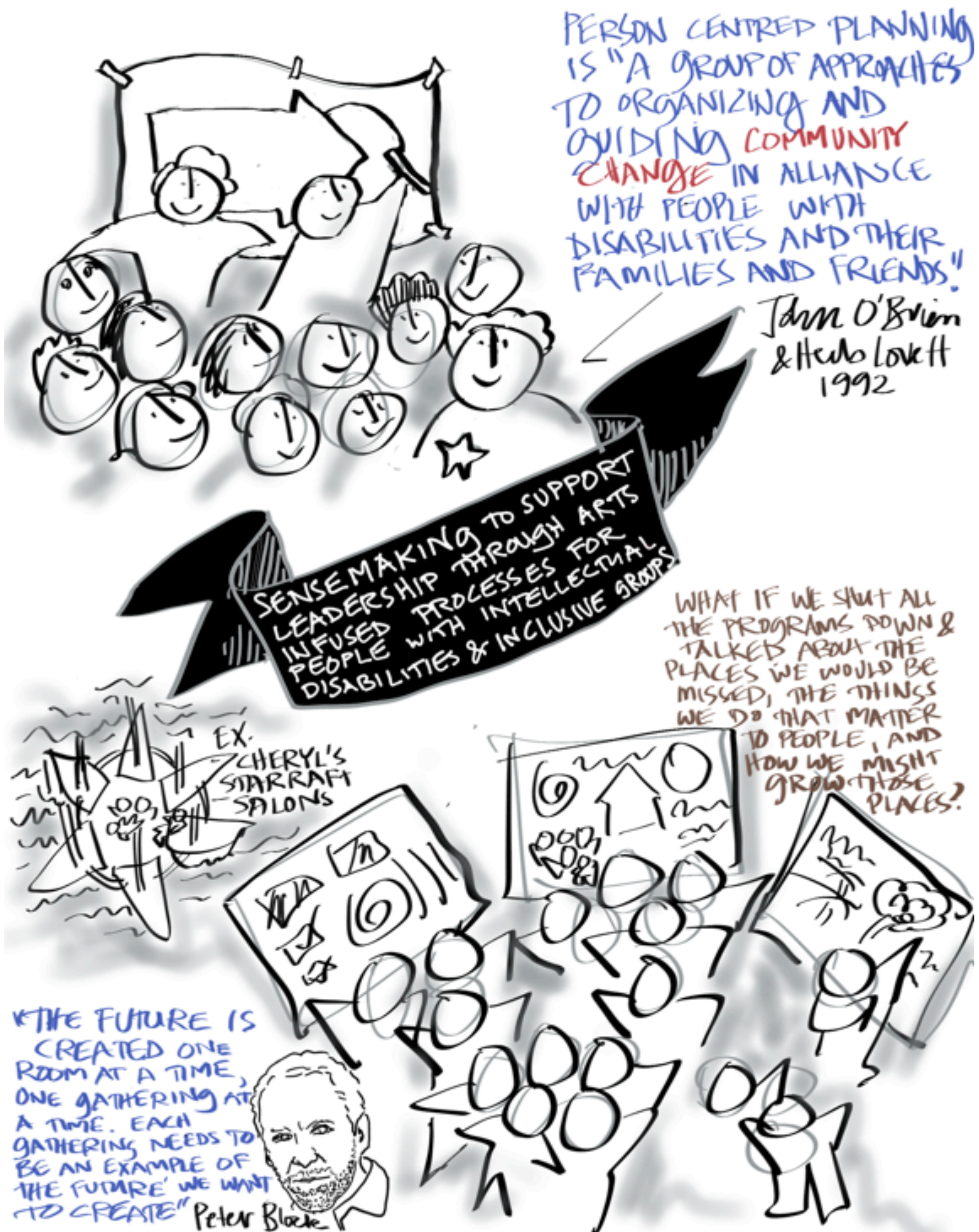


Figure 9. Graphic rendering of this paper for discussion with people with disabilities.

Publishing History

A version of this paper titled “Sensemaking Through Arts-Infused Person-Centred Planning Processes” was published in *Sensemaking: Presence, Emergence and Connection Through Visual Practice*, edited by Brandy Agerbeck, Kelvy Bird, Sam Bradd and Jennifer Shepherd (Johannes, 2016).

Introduction

This paper examines some experiences of facilitation of person-centred planning for people and planning for community development with groups that include people with intellectual disabilities. Person-centred planning has become a standard expectation in best practice supports and services for people with ID over the last 4 decades (O'Brien & O'Brien, 2000; Sanderson, 2000), with many resources available to support it (Kilbane, 1999) and is relatively well researched in both intention (e.g., Wehmeyer, 1999; Wehmeyer & Abery, 2013; Wehmeyer, Bersani, & Gagne, 2000; Wehmeyer & Laurence, 1995) and practices (Cummins & Lau, 2003). However, the inclusion of people who think and communicate differently as equally participating leaders in groups of community leaders has been much less researched, even though they effectively exist in agencies, government, and community sites such as workplaces and volunteer organizations (Johannes, 2013a).

Early on, O’Brien and Lovett (1992) described person-centred planning as being not merely a way to plan for the lives of people with disabilities, but also as “a group of approaches to organizing and guiding community change in alliance with people with disabilities and their families and friends” (p. 5). It is this idea of “community change” that is of interest given that person-centred planning incorporates not just the tools for changing lives, but also the potential to call on the invested networks of people to work towards supporting inclusion and aspiration in their mutual communities.

John O’Brien (as cited in Sanderson, 2000) has said, “Person centred planning begins when people decide to listen carefully and in ways that can strengthen the voice of people who have been or are at risk of being silenced” (p. 3). The theoretical, and experiential, underpinning of this paper is that just as it has been possible and useful to

involve people with have been labelled as intellectually disabled in planning their own lives, it is equally possible to plan for and assume their active, authentic participation as leaders in the community development, services and social justice initiatives that interest them.

In this paper, I will first consider the uses of person-centred planning which are already somewhat understood and familiar to those in charge of policy development, service provision and funding, and then examine how related processes have been and might be used with larger inclusive decision-making groups. Given that my methodology has been experiential over some 20 years of learning about these processes, often led to them by people with disabilities seeking ways to be involved as leaders, my approach here is to recount stories of people and events related to planning and inclusion in response to their frequent request to focus on narratives (Johannes, 2017). Thus, I have synthesized the experiences of different individuals to construct some experiences of person-centred planning that are typical, although by their nature these are extremely individualized events. I will also reflect on my own involvement in previously documented community development projects, in the context of the body of research about person-centred planning and inclusion in participatory groups of leaders.

A challenge, and a gift, of exploring such ideas in the company of a marginalized group of people whose experiences have not been well documented is that it requires new ways to explore and research. Social constructionism's prioritization of the individual as a network and the self as co-constituted, out of which action and change occur, "replaces the self-contained, pre-social and unitary individual with a fragmented and changing, socially produced phenomenon who comes into existence and is maintained not inside the skull but in social life" (Burr, 2003, p. 104). This sense of the co-constituted self (Gergen, 2009) allows us to better understand how person-centred planning works within the networks of the focal person, and then to extrapolate to how similar methods can work for inclusive community development. As Shelley Moore (2016) has stated, "If we look at inclusion as a concept of teaching to the diversity of all,

rather than just a special-education initiative" (Introduction section, para. 11) we can bridge the gaps that specialization rest on:

> *We are diverse, all of us. We all have strengths, we all have stretches, and we all need to get better at something. The difference in teaching to diversity, however, is that we don't start with our deficits; we start with our strengths, and this includes students, teachers, support staff, custodians, bus drivers, and parents.* (2016, Introduction section, para. 11)

Background

Deborah Ancona (2012) of M.I.T. says that sensemaking

> *refers to how we structure the unknown so as to be able to act in it . . . coming up with a plausible understanding—a map—of a shifting world; testing this map with others through data collection, action, and conversation; and then refining, or abandoning, the map depending on how credible it is.* (p. 3)

Visual facilitation, drawing pictures of a person or a group's conversations, is a way of mapping what's credible within constantly shifting dynamics, and their responses lead us towards different "truths," which become potential plans—does this look like what you want? Does this seem possible? Like something everyone can work on together? The graphic mirrors the dynamics of the people in the room and plans rendered to their essential parts in simple graphics become the visualization of a changed world.

Sensemaking has been a useful concept to bring to planning for and with people with (or without) disabilities, team building or projects, because as a mode of being it intentionally listens for clarifying questions and directions. From these, diverse groups create "future forming" plans and the skilled facilitator uses processes that can be as light as a feather and yet generate changes that may have been desired for years.

Traditional forms of planning for people with ID focused on deficits and were based on bureaucrat forms out of a medical model of supports. Often a range of professionals would sit together with stacks of papers that were impossible for families and people with ID to understand, and determine which of a limited number of programs their deficits qualified them for. Sometimes the family and person were not even present as their future was determined. How this felt for families was are described by Meyer Shevin (2002) in a much-quoted passage:

> *Imagine this: You arrive, unaccompanied, at a party you've been told in being held in your honor. When you get there, you find that all the others are wearing formal gowns and tuxedos—everyone but you. There is an elaborate array of food and drink, but you are allergic to everything on the buffet. Periodically, the other guests start to engage in an elaborate, intricate dance, which you have never seen before, to music you cannot hear. Hardly anyone speaks to you; eventually, someone does, but turns away before you reply. You feel increasingly helpless and ghostlike.* (Shevin, 2002, p. 197)

Helen Sanderson (2000) defines person-centred planning as a family of approaches with some common values and principles used as a lens to support a person with a disability to communicate what they want for themselves by focusing on two questions:

- Who are you, and who are we in your life?
- What can we do together to achieve a better life for you now, and in the future?

She points out that it is not simply a collection of technical processes that replace the more medically focused planning models used in institutional environments, but begins or reinforces "a process of continual listening, and learning . . . [about] what is important to someone now, and for the future; and acting upon this in alliance with their family and friends" (Sanderson, 2000, pp. 2–8).

Person-centred planning does not simply replace former conceptualizations of planning, but incorporates five important ideas:

- first, the person is at the centre of the planning, consulted throughout, and chooses who to involve and when and how to have the planning event;
- second, that family and friends, the person's network, are partners in planning through an interdependence-based model;
- third, that the planning reflects the person's priorities and capacities from a strengths-based perspective, as well as being informed about what supports they will require to accomplish their goals;

- fourth, that the planning results in wanted, often transformational changes in their lives, not only the services and supports they require (but may require those services and supports to change) and,
- fifth, that the plan incorporates ways and means for further listening, learning, responsiveness and actions (Sanderson, 2000, pp. 2–8).

O'Brien (as cited in Sanderson, 2000) expands on this by focusing on the planning event as an opportunity for airing differences, defining dreams and building reciprocal relationships:

> *Person centred planning offers people who want to make change a forum for discovering shared images of a desirable future, negotiating conflicts, doing creative problem-solving, making and checking arrangements on action, refining direction while adapting action to changing situations, and offering one another mutual support.* (p. 8)

In the end it is, Sanderson (2000) writes, "a completely different way of seeing and working with people with disabilities, which is fundamentally about sharing power and community inclusion" (Sanderson, 2000, p. 8).

An important part of this difference is that alternative forms of communication, such as graphic recording, are used to help the person and their network understand each other. Another difference is the focus on simple dialogic processes that can be used by amateurs as well as professionals in the places where people live and life happens (O'Brien & Lovett, 1992; O'Brien & O'Brien, 2000). If it is true that each of our networks, our circles of friends (Saul, 2005), is the smallest unit with which to begin building community then each event changes the world just a little and begins to build a future that welcomes diversity through strengths-based approaches and a focus on the person's contributions to their network and community.

This happens first simply in that the planning event is an invitation to the person's network to be involved participants, second in that the network has the potential to expand in both numbers and roles, and third in that the person's goals can incorporate an increased social presence by focusing on more "valorized" roles or roles in new places. The person, their network and the places and communities they are part

of all have the potential to grow and become healthier through the increased diversity of their membership as, “to speak of the health of an isolated individual is a contradiction in terms” (Berry, 2002, p. 146).

Figure 10. Graphic used in invitations to the focal person’s network.

Familiar person techniques can be incorporated into ways of bringing people with ID into larger conversations about community, work teams, their own groups (such as People First), and so on. Person-centred planning has also been perceived as having the potential to challenge organizations and community to examine and increase their own capacity (O’Brien & Towell, 2003). Gergen’s (2009) idea of the person as inseparable from their network is particularly important here. At the intersections of the goals of individuals and their communities, gaps in supports in the person’s networks, involved agencies, organizations, governments, and communities are often identified. These require change, and the design of PATH incorporates the opportunity for a step-by-step analysis that bridges the personal and community levels by imagining something different. In a reciprocal cycle of planning, gap identification and the planning to identify steps to address the gaps, the potential for change occurs:

> *The word **context** points our attention away from the details of how person-centred plans get made to the environment in which person-centred plans get implemented. The word **strategic** points our attention to capacities that must be developed on purpose, over time, if person-centred plans are going to lead to real positive differences in lots of people's lives.*
>
> *So thinking about person-centered planning in its strategic context means identifying what needs to change in specialist services and what needs to change in mainstream services (like housing, transportation, education, benefits, and services that help people get into jobs) if big numbers of people are going to be able to turn good plans into better lives. These changes will only happen if people work together across the boundaries that separate services. It will be some time before new ways of working become widely enough established to make it easy to gather the resources to implement a person-centred plan without a good deal of creative problem solving and negotiation.* (O'Brien & Towell, 2003, p. 1)

Often in person-centred planning, the members of the network that are present are required to change in capacity or roles. For example, a non-verbal young woman with an intellectual disability, identified as very vulnerable and constantly supported by her parents, took the opportunity in her planning to say she wants to take a holiday with her sister. Within the family dynamic she is identified as someone who has trouble with responsibility. In that moment, as the facilitator, it is possible to see the parents' hesitation, but also their reconsideration of their children, as their daughter moves from a contemplation of change to a public decision, conveyed as she stands up straight and points at her sister with a decisive glint in her eye. Her sister's initial startlement is followed by consideration and what seems an equally firm declaration that she will accompany her. In effect they begin to lean into the roles they both want to have when their parents are no longer present, and the success of both their futures are more assured. All of this happens within moments and is conveyed, for the most part, without words. The young woman has never had words, and this has always been considered a deficit, but in this moment none of them have words, yet they are actively communicating and are all part of the same plan in which everyone is moving forward together. The parents have a moment in which they lean forward as if about to object, and then their shoulders come down and when they lean forward again, it is into a whole new world.

I have come to think that another aspect of good person-centred planning is whether or not it similarly challenges organizational supports to change. For example, in a planning session an individual with an intellectual disability identified working at his local community centre's childcare centre as a goal. The community centre has a long tradition of supporting student work experience placements and he had enjoyed his time at the day care there. When he took a digital copy of his PATH to the centre, they realized that, first of all, they had no employees with disabilities. They had not thought about this and it seemed a priority for them. As they thought it through, they realized that he was a great candidate for a position in their day care, but some policies would need to change. Their caring for the person that they knew created the conditions for social change within the organization. The personal becomes political and realization activates further planning.

By examining some processes, features and dynamics of person-centred planning we can extrapolate and plan for larger inclusion focused decision-making groups.

Person-Centred Planning

Some organizations have made person-centred planning central to all their work. PATH, which at one point stood for Planning Alternative Tomorrows with Hope but now simply indicates a method to identify and follow one's path, was developed in contrast to the kinds of planning processes families and individuals were familiar with, in which stacks of papers and forms to fill out were privileged by a number of professionals who might or might not have knowledge of the actual person and their network, advised them on how to live. While PATH is not the only person-centred planning process, it is an exemplary one for many reasons. It is flexible and useful to many different kinds of persons and situations, can be facilitated by people who have just a little experiential training, gives the participants a simple way to break down complex dreams, goals and action steps and people with ID can come to master their own planning processes as they experience the same processes repeatedly.

PATH as an exemplary form of person-centred planning.

PATH was invented by Marsha Forrest, Jack Pearpoint, and John O'Brien in the 1970s (Sanderson, 2000). It was one of the early alternatives to the kind of planning that was happening in special education and services – planning driven by professionals, filling out pre-determined forms using "specialist" language embedded in rigid roles. The role families and folks with disabilities had been given was to passively attend as professionals worked through a number of domains by tallying up at what was problematic in each one. In comparison, PATH was a sequence of open-ended questions that assumed everyone in the room—including the person with the disability—had input that mattered. It also assumed that everyone had strengths that could be approached appreciatively, and that they could contribute to their communities.

The originators of PATH wondered what might happen if people were encouraged to dream? If there were ways to record their dreams which everyone could see and understand (no matter what their literacy levels) and ways to plan to get from where they were to where they wanted to be?

PATH is almost always a co-facilitated with a graphic recorder and a facilitator and is designed to be a simple process that amateurs can use. The steps of the process are as follows:

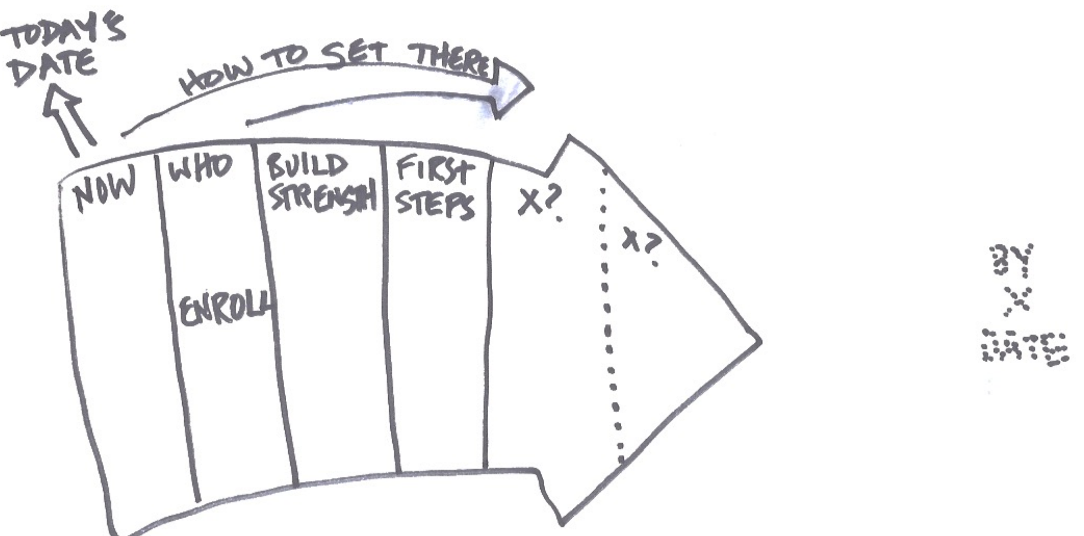


Figure 11. Steps for the PATH process.

Begin with a dream.

A PATH starts with the facilitation of the person's (or group's or project's) dream: What does it look like? Often they ask, "If you could have anything—no holds barred—who would be there? Where would it be? What would surround it? How would it feel?" The graphic recorder draws the elements of the dream.

Looking back from a future time.

The facilitator then moves to the "positive" and "possible" section. Sometimes this involves a quick guided meditation about taking a time machine into the future and looking back on what dreams have accomplished in a given time (often, 2 years). While the dream section might have included things that seem impossible—someone who can only move one finger wants to work and be self-supporting—in this section things must be doable. Within 2 years what might be accomplished towards this dream? They might "remember" (from their future time machine) they got a part-time job. Questions to deepen this might have to do with who would be they be working with? What kinds of things might they be doing? For example, someone in the group remembers that their church needs someone to staple the newsletters each week—it only takes one finger . . . possibilities accrue and each question, each detail, builds a picture of a desirable future.

NOW?

The facilitators move down the parts of the PATH to the "NOW" section—how are things right now? What feelings are people having? For Brent's family, speaking out of their knowledge of him, there was excitement about the future that felt even more "positive and possible" given the full house of all the people who responded to the invitation to his meeting—this act of planning for the future is in itself an act of creating that future by bringing these people together.

WHO?

The facilitators have usually explained the PATH process as an opportunity to invite others in, often for the first time, and welcome them to take roles in people's lives. As a participant said, person-centred planning activates our tribes. This is also

where those people who might be crucial to future plans are listed, often in terms of what they will bring. For example, “yoga teacher.”

Building strength.

As participants look at the emerging PATH graphic it becomes clear that a new picture of a possible future that matters is happening, and might require the identification of ways to continue to be strong, or to become stronger. To get to the “positive and possible” changes that are identified, the participants might have to agree to get together to share meals every month, for example.

Step by step.

The first of these steps is “first steps”—what few things might be done in the next week or so that will lead the focal person and their network into this desired future? After this, things are broken down into manageable chunks—possibly into periods of months or seasons. In this section the facilitators assist the network to create milestones for the emerging plan, as if one is looking back from the viewpoint of having accomplished those goals.

In PATH sessions, which can be a few hours long, new relationships are formed, and old relationships are transformed. A new future is depicted, and it is one that the person (with their network) can easily visualize with the help of graphics and facilitation.

Figure 12. Ty with the PATH his network has helped him imagine and plan together.

Figure 13. A network of friends finish off the PATH with a group shot; the laptop was the vehicle to include a network member who lived out of town.

What had seemed impossibly ambitious becomes possible.

Often, this sense of possibility is directly related to how person-centred planning allows for the opportunity of invitation. A dream that might have seemed impossible because even the steps to accomplishing the goals seemed too daunting, becomes far

more possible when one is surrounded by supporters who have participated in the planning and agreed on ways to help one.

How Person-Centred Planning Calls for Social Change

In the process of someone's PATH participants who are less familiar with the lives of people with disabilities often realize that their assumptions of what typical lives are like, that one will work at a job and be in relationship and pursue one's goals, are not always true for people with disabilities. What is thought of as a typical wealth of choices available to all is suddenly realized as privilege. Thus, a PATH, even for one person and their network, becomes a potential emancipatory action. As one parent termed it, those who care about the person become "accidental activists" and then part of a political movement that clarifies as a visual map, on the wall of someone's home, that they might be supported as equal citizens in just a few identified steps.

The insanity of supports that do not allow for choices about where people live, who they live with, where they spend their days and who supports them becomes evident, and radicalizing. In this way we can see PATH and related person-centred planning methods as tools that can initiative a transformative social movement. The wall-sized drawings of a bricolage of dreams becomes a vision of possibilities that creates a kind of chorus, demanding systems and governments to change and fostering a transformed and welcoming world for us all.

Brent's vision.

Brent is a young fellow with autism sitting at the centre of a circle of about 20 people who care about him. On the verge of adulthood, about to leave high school, he has invited his family, some family friends, people from his school, and others who have supported him from every period of his life, including when he was a toddler, to dream of what his adulthood might be. He hates meetings and, as often happens in PATH, while he arrived unhappy and glowering, he is now grinning, hugging, and delighted to be here with people who love him and snacks he like. He sits between two friends, taking turns leaning against them.

Brent does not speak in ways we expect. He has decided as of a few years ago to trade in his voice for a xylophone and now he plays songs. Formerly, professionals might have ticked off "voluntary mutism" on a form. While he communicates like this with his close family, he has not demonstrated how this works to his larger network. Friends from his school band are excited, as they know him as an adept musician but had not considered this as communication.

He plays along with his boombox to three songs he has lined up to introduce this topic of planning his adult life to his network, but when the second song is done, suddenly shakes his head "no," goes to the boombox, finds another song and plays an Elvis Costello song instead of whatever he had intended:

> *Oh it's not easy to resist temptation*
> *Walking around looking like a figment of somebody else's imagination*
> *Taking ev'ry word she says just like an open invitation*
> *But the power of persuasion is no match for anticipation*
>
> *Like a finger running down a seam*
> *From a whisper to a scream*
> *So I whisper and I scream*
> *But don't get me wrong*
> *Please don't leave me waitin' too long*
> *Waitin' too long*
> *Waitin' too long*
> *Waitin' too long*
> *Hey*
>
> *Oh oh oh oh oh.* (Costello, 1981, para. 1–3)

Brent hits the keys with perfect timing and many of those who care about him have tears running down their faces. When he is done, his mother, a little shakily, thanks the network for coming to support his dreaming and planning for his adult life and introduces the facilitators.

Figure 14. Graphic, brainstorming Julie's gifts.

The "purpose driven life" his network begins to describe for Brent includes going to university, being part of his community, doing varied work, being with animals and playing music. The graphic facilitator draws the life that is already partly happening, and also draws the next part of his life, which had not been clear to everyone yet. As one mother said, "In this process we are creating the future we want by leaning into this vision as we create it."

The vision of his friends and family accrues on the page, the facilitator moving people through the parts, asking insightful questions, deepening and clarifying the dream, while the graphic recorder documents his present and future – a job, music school, friends, communication, safeguards, an apartment, a room-mate.

Three typical kids, without disabilities, who have shared inclusive classrooms with him for most of his life have come tonight and as the vision accrues they ask if they can add to the picture's possibilities. There is a plan for Brent to enter a specialized "pre-vocational" class for people with autism at a local community college. "Why isn't Brent coming to university with us?" they ask. They propose sharing an apartment. The graphic recorder quickly draws over the special program and is now drawing apartments, parks, musical instruments, a dog—someone course corrects on Brent's behalf. He does not like big dogs, only small dogs, so he would like the dog to be drawn smaller. Brent nods. The graphic recorder uses a sticky label to cover up the big dog and re-draw a smaller dog. Brent smiles and everyone chuckles. He has been heard, and something in them all resonates with this, as if they too have been heard in a new way.

Other corrections come now fast and furious, as if given permission—the boys do not want to live on the tree-lined suburban street in the picture drawn them, they want to live downtown. The trees become streetlamps and buildings. Brent's parents frown a little, but stay brave. They can let go of their safer more assured plan and will support whatever he really wants, if they can only discover what it is, and from Brent's reaction they know this picture encompasses the future he wants.

This change in vision means he will not attend the small local college they planned for, but the bigger urban university. His sister reassures their parents that she already attends the city university and knows the processes he will need to go through. A neighbour, who came because she was invited but was not sure how useful she might be, offers to introduce them to the registrar of the university, her brother-in-law. "He's going to love Brent!" she says. The graphic recorder draws Brent in the big city. Ideas are hurtling across the room, people are laughing, their voices soaring, coming together in a kind of web of hope that the whole network is increasingly caught up in. Most of them are now on the edges of their seats, excited to offer supports and introductions to new places, new people and new possibilities. Brent is laughing: his future life looks amazing. He was predicted able to stay for a maximum of 20 minutes, 3 hours later he is still grinning and nodding and high-fiving his friends.

Julie's PATH.

As Julie described her life and what moved her: music, people, connections, contribution, having meaning, the graphic recorder first drew everything in her brainstorm (see Figure 15), and then created an icon out of these, coming together as a kind of heart-beat.

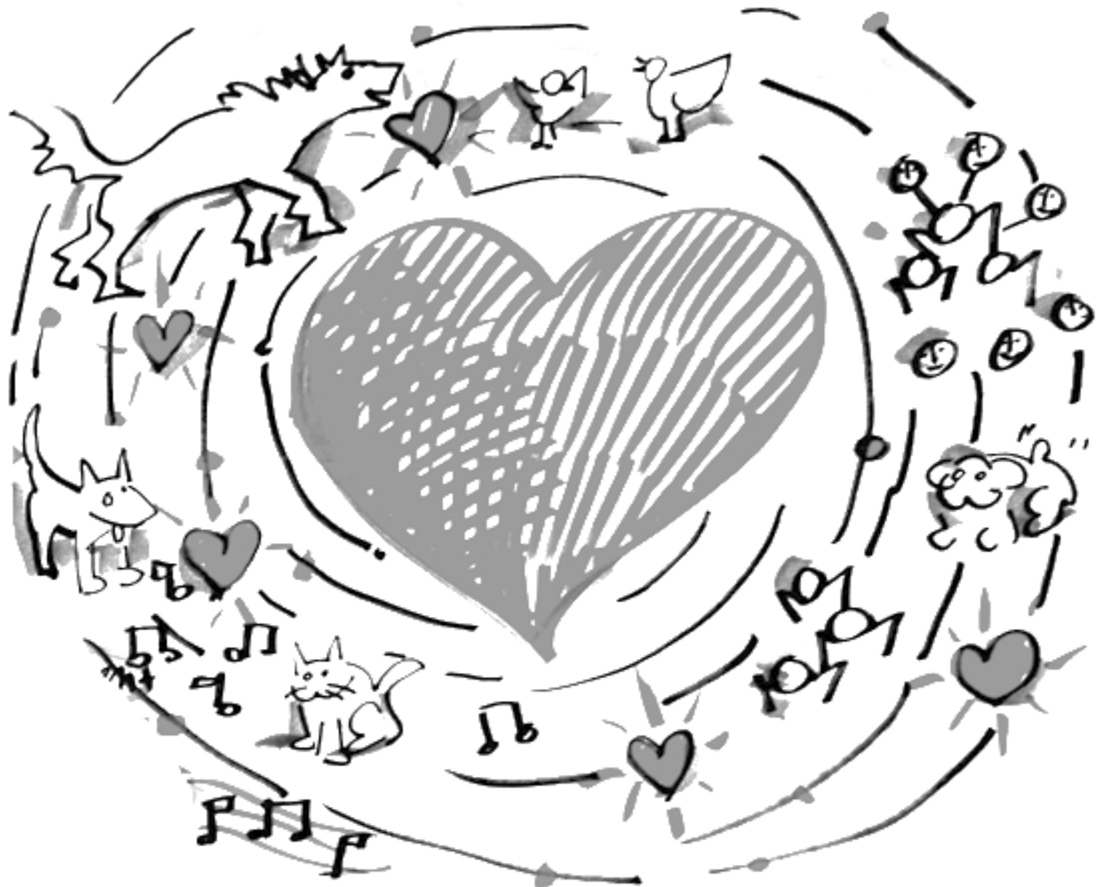


Figure 15. Julie's icon – a symbol for what she loves and represents to those who know her.

As the evening's planning continued, Julie's whole PATH developed to look something like this:

Figure 16. Julie’s whole PATH.

A year later, Julie has left the job that did not match her expectations and created a different role in her community, in which she cares for more animals and is now part of two bands. PATH-finders, the focal persons for the planning, often report back on the progress of their shared vision and Julie reports that she is playing at lots of concerts, gigs, and venues. Unable to find the choir that had been part of her dream, she has just put up announcements about creating a new choir and is inviting others into her vision of a world where everyone can sing together.

Person-Centred Planning as Community Organization and Guidance

A difficulty with the more granular approaches which person-centred planning often devolves to is that the more embedded it is within systems the less emancipatory as it becomes about the stories of one person, or one network, rather than the shared narrative of a group of people. It is also subject to misuse, as when agency representatives facilitate planning for organizations that only offer choices that are possible within the agency; such planning is a perversion of the idea that person-centred

planning is about the potential to access the whole community. Thus, person-centred planning is also about the potential to change communities.

In their national practice guide to promoting self-determination for adults with ID researchers found a correlation in the research literature between person-centred planning and increased community access, network involvement and presence (Vatland et al., 2011). In their review of the processes, Becker and Pallin (2001) suggest that organizational explorations of person-centred planning should include these steps in one form or another:

- Getting to know the person with the disability.
- Assembling a team to develop a comprehensive personal profile of the individual, known as the "focus person."
- A clear, unrestricted vision of success is developed by the team, which guides the rest of the process. This vision involves the person's talents and dreams, and includes new roles he or she can fill in society. (p. 4)

It is easy to miss this idea of "new roles" and the more subtle idea of "unrestricted vision," as most researchers do not state that it is the systems of support that often restrict the vision of belonging. For example, researchers Steere, Gregory, Heiny, and Butterworth (1995) cite two main papers in their examination of person-centred planning. While in one of these papers the authors describe person-centred planning as "processes [which] link current activities with anticipated events and living conditions" (p. 1), nowhere in the very thorough article does it relate person-centred planning to any kind of prospective community development—it is about planning for services, housing, leisure, and so forth, not about emancipation, leadership, or community building.

While it is relatively easy to see that people with intellectual disabilities should have reign over their own lives, they are not much recognized for their activism around the world in hundreds of local self-advocate groups, state and provincial groups, national and international groups such Inclusion International which represents over 200 member federations in 115 countries throughout the Middle East, Europe, Africa,

the Americas, and Asia Pacific (Inclusion International, 2011, p. 1), and more recently for their involvement in the United Nations (2006) *Convention on the Rights of Persons with Disabilities*. There are also many individualized service models in British Columbia in which the focal person with the disability is the decision-maker and leader. However, even the title of the United State's largest study of self-advocate board members for service providing organizations, Beyond Tokenism, indicates that there are difficulties in finding common ways for people with and without disabilities to understand each other and plan for community development (Friedman & Beckwith, 2014).

My own introduction to graphic recording was through national People First events where David Hasbury recorded the board's proceedings. John O'Brien (1989) has written about Hasbury's move from being a teacher in segregated schools to thinking more deeply about ways to invite students with special needs into student belonging, to working with welcoming all members of diverse communities. It would be 10 years before I found anyone else working in this way and began my own courses of training, with Hasbury pointing out that while there was one lineage for the work to the organizational concerns of the silicone valley entrepreneurs, there was another that led to Freirean concepts of community-based education, written about by authors like Gatt-Fly (1996) in *Ah-hah*! *A new approach to popular education*.

Cheryl's star raft salons.

Cheryl initially simply wanted a plan, and she had heard about person-centred planning. She had recently turned fifty within a family that had always defined a carefully circumscribed path for her within their cultural tradition, created she thinks when she was in about Grade three and they realized she had learning challenges. This plan had not only not worked out for various reasons, but she now found herself alone. Instead of being cared for, she had become the primary caregiver for her aging mother, who had moved into a care home. On the one had, she was now without support, but found herself with a new sense of freedom and hungering for self-actualization.

When the process of person-centred planning was explained to her, she could think of only one person to invite, and she was not sure if they would come. Her

concern turned out to be that even if she did think of people to invite, they would all say no and that would be crushing. However, with some planning and supports for a process of gradual invitation-making over 7 weeks, on the evening of her PATH seven people were excited to be there. Cheryl made interesting and unexpected choices about invitations and, for example, had asked the Director of Policy Development for the provincial branch of government that funds disability supports. She did not know her well but felt she would be a good asset and the Director was glad to be involved at such a personal level given that her work in the field had become quite abstract over the years. People she knew well or just a little all made great efforts to be present and were excited about her invitation.

As the PATH continued, her goal to learn more about self became a tentative plan to investigate building a leadership curriculum with a small group of self-advocates that she had not yet met but felt she could find. When she invited them in to meet about this idea, they together came up with the idea of a year-long self-designed leadership curriculum that would focus on skills development and networking. They identified a new model of community development developed by David and Faye Wetherow, the Star Raft, as their possible method (Wetherow & Wetherow, 2016). David Wetherow was interested in co-hosting their events, the government people who had attended her PATH were poised to fund the initiative, and together developed a year-long curriculum, supported by the researcher and colleagues.

The focus of the curriculum was the development of networks to support their leadership through relationships. Cheryl, now a dedicated fan of PATH, suggested to everyone that part of their work be to have and participate in PATHs for each other. Monthly meetings were based on the idea of a salon:

> *A salon is a gathering of people under the roof of an inspiring host, held partly to amuse one another and partly to refine the taste and increase the knowledge of the participants through conversation. These gatherings often consciously followed Horace's definition of the aims of poetry, "either to please or to educate."* (Whiteside, 2017, para. 6)

Cheryl, formerly perceived by herself to be alone and powerless, would be the "inspiring host." Throughout the year they would each have a PATH or other person-centred planning event, and each month would focus on a different discussion and they would invite in another community member to participate. Each month's events were graphically recorded for the group and as they shared their goals and aspirations and updated each other, they also supported each other. Monthly guests, as well, were inspired to support the group's members.

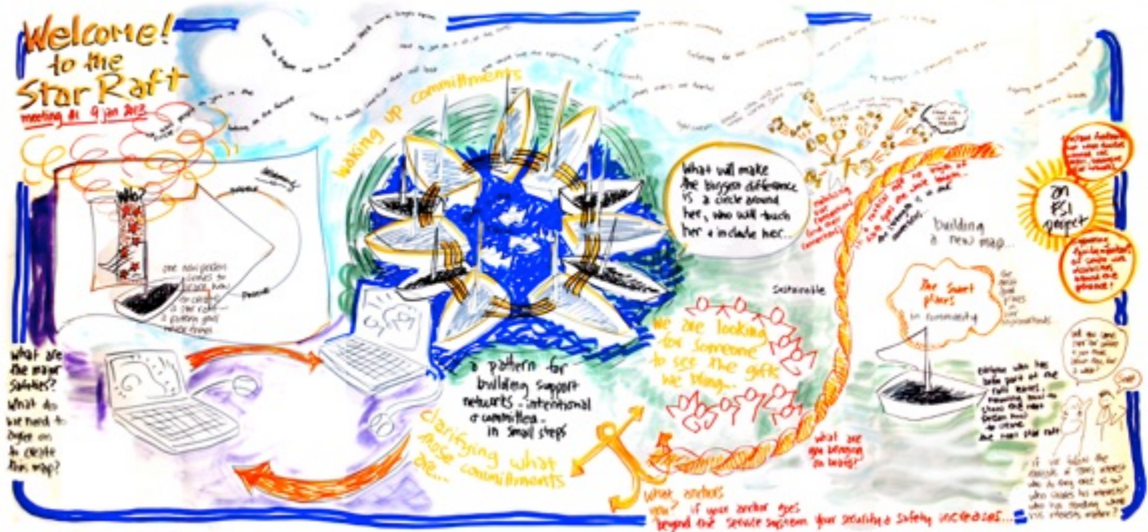


Figure 17. *Cheryl's Star Raft Salon graphic for January*.

An independent consultant was brought in to interview group members at the end of the year and collected feedback, and a small book was created based on the graphics, the events, the feedback and reflections. Invitations to members of the public were greeted warmly: "People wanted to learn more about public speaking – so we asked Toastmaster if someone could help. They sent TWO people" (Spectrum Consulting, 2014, p. 51). The interviewer reflected, after talking to group members,

> *Teaching and learning are powerful tools for empowering leadership and building a strong and vibrant community of inclusion. The Star Raft allowed people to identify what they wanted to learn more about and then found people within the group's extended networks who knew about each topic. When learning took place in the Star Raft group, people were equipped and supported by the network that was created to begin practising and experimenting with new skills and knowledge.*

> *With the support of a network of friends who are focused on learning and planning for their lives, people are more able to plan out and accomplish their goals.*
>
> *The Star Raft was a fun and easy way to turn dreams into action.* (Pauls, as cited in Spectrum Consulting, 2014, p. 41)

Ted's talks.

The Vernon Self-Advocacy Association (Johannes, 2013b) suggested a project in which they and their peers would "show people we matter to our communities AND we show them they can matter too" (para. 2). They wanted support to facilitate these conversations and document the results through drawings, which they would then use to explain their lives and priorities to their supports and their communities. In Vancouver, another group of self-advocates helped expand on this idea to create a plan to host events in three communities. In each community a self-advocate group would host peers and friends and assist in the facilitation of a strengths-based conversation about these ideas, and afterwards would host a reception to which self-advocates would invite the people they wanted to learn about their lives. They were supported to apply for funding with this drawing of their plan:

Figure 18. Graphic: Inclusive Research Project: community mapping.

Using graphics to imagine and then break down the project into parts, a proposal for an "Inclusive Research Project: Community Mapping" was written and found funding

through an award from the Ashoka Foundation and also received a B.C. Ideas Award for "solutions for stronger communities" (Ashoka Foundation, n.d., para. 2).

Prior to each event, opportunities for discussion and dialogue with each host group were created: as in person-centred planning, who might you invite that would be a person of influence, or someone who you wanted to understand your life better? What might you do to make them feel welcome and receptive to listening to different ideas about how you live and want to live? Events were co-hosted by self-advocates, and many community leaders came after being invited by self-advocates they often did not know well, but felt that they wanted to know more about.

Figure 19. Self-advocate brainstorm on who might be invited in by people with disabilities, to dialogues about belonging, and how they might host them.

Iteratively, self-advocate organizers had ideas about expanding the practices of the community conversations. In Victoria they replaced the idea of nametags with printed tags which said things like "a gift I share with my community is." In the following graphic these form the wave at the bottom of the sheet.

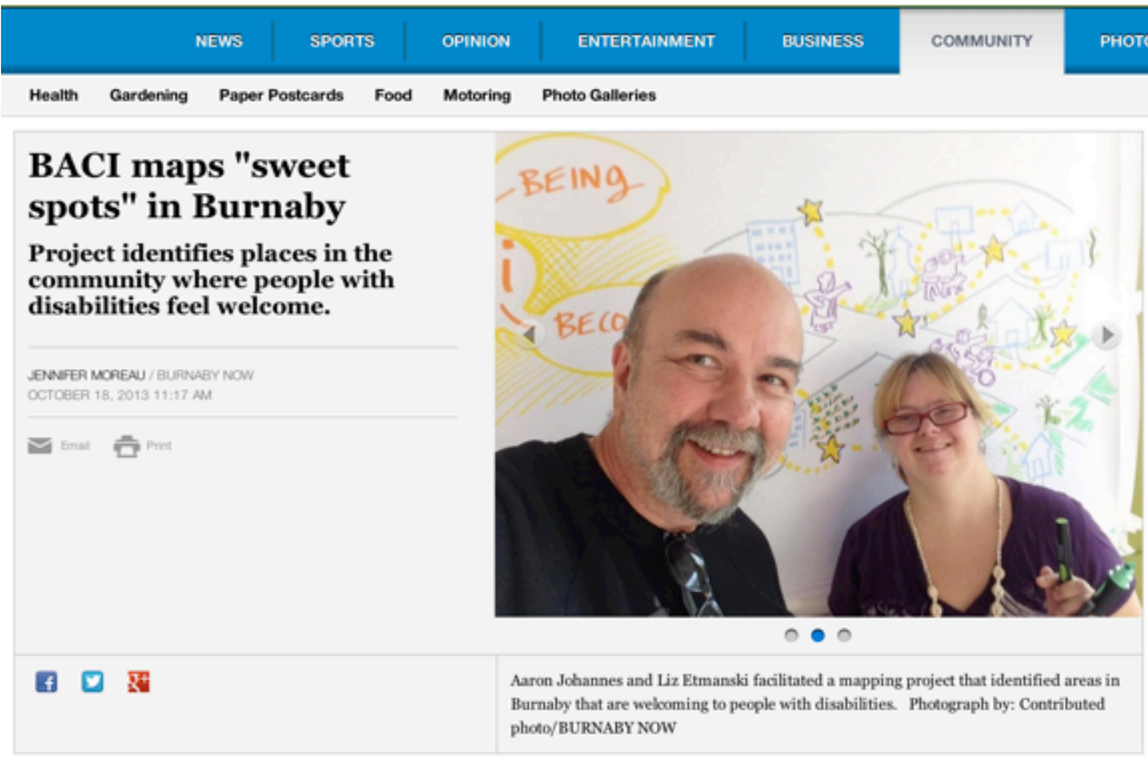
Figure 20. Community mapping, Victoria.

Figure 21. Community mapping, Victoria, detail.

Guests included several mayors, politicians and community leaders and educators. Often they would say things like, “They have never asked me for anything before, so of course I had to come.” They were excited to understand more about people’s lives and capacities. One politician said that he had never understood before that people want to work: “This will change every decision I make during my political career.” A executive from the local Parks and Recreation Association looked at a list of ideas about access to community centres and said, “I can make three of these five things

happen tomorrow; the rest will take a year. I had no idea these were limitations." In another city, someone responsible for housing looked at all the drawings and said she now understood why no one wanted to live in the segregated housing complex she had worked so hard to have built: "They want to be part of neighbourhoods. I should have asked." One pre-school teacher whose classes included children with disabilities said, "This is the vision I want to hold in mind as we work together with these children and their families."

Figure 22. Community mapping – being, becoming, belonging.



NEWS | SPORTS | OPINION | ENTERTAINMENT | BUSINESS | COMMUNITY | PHOTO

Health | Gardening | Paper Postcards | Food | Motoring | Photo Galleries

BACI maps "sweet spots" in Burnaby

Project identifies places in the community where people with disabilities feel welcome.

JENNIFER MOREAU / BURNABY NOW
OCTOBER 18, 2013 11:17 AM

Email Print

Aaron Johannes and Liz Etmanski facilitated a mapping project that identified areas in Burnaby that are welcoming to people with disabilities. Photograph by: Contributed photo/BURNABY NOW

Figure 23. BACI maps 'sweet spots' in Burnaby.

While it is often difficult to get media coverage of strengths-based self-advocate initiatives, in almost every event the media came to cover the reception (e.g., Moreau, 2013), as well as agency and government leaders, educators, mayors, and elected civic, provincial, and federal leaders.

Summary and Implications

The continuing sense of people being left out of events and decision making about their lives, the groups they are part of and their communities occurs within decades of research of alternative experiences in how to involve them in more equitable ways. For some reason, just as it has been difficult to translate research into practice and bring those worlds together, it has been difficult to make the leap from person-centred planning methods to community development methods. The following is a list of just some of these assessments, initiatives, and projects: Becker and Pallin (2001),

Block (2008), Goodley (2000, 2005), Kendrick (2012), Kitchin (2000), Kunick (2007), Masny (2013), McKnight and Block (2012), Merkley (2007), Michell (2012), O'Brien and Lovett (1992), Patty (2013), Pitonyak (n.d.), Roets (2008), Stainton (2005), Steere et al. (1995), Walmsley and Johnson (2003), Wehmeyer (2013), Wetherow and Fryfield (2013), and Worrell (1988). Many of these suggested processes come out of person-centred planning, while some are related but more focused on what Peter Block (2008) has called *Structures of Belonging*. He writes,

> *This is not an argument against leaders or leadership, only a desire to change the nature of our thinking. Communal transformation requires a certain kind of leadership, one that creates conditions where context shifts:*
> - *From a place of fear and fault to one of gifts, generosity, and abundance*
> - *From a belief in more laws and oversight to a belief in social fabric and chosen accountability*
> - *From the corporation and systems as central, to associational life as central*
> - *From a focus on leaders to a focus on citizens From problems to possibility.* (p. 85)

In *The Geography of the Genius,* Eric Weiner (2016) looks for commonalities in those places and situations where innovative thought has developed and prospered into world shifting concepts and actions, such as ancient Athens, Florence and the Silicon Valley. He offers, as a counterpoint to Richard Florida's ideas that it is "talent, technology and tolerance" (Florida, Mellander, & Stolarick, 2010, p. 284) that matter, that it might rather be

> *disorder, diversity, and discernment. Disorder, as we've seen is necessary to shake up the status quo, to create a break in the air. Diversity, of both people and viewpoints, is needed to produce not only more dots, but different kinds of dots. Discernment is perhaps the most important, and overlooked, ingredient.* (Weiner, 2016, p. 324)

Replacing old methods of planning with newer ways of bringing groups together on behalf of a person, a cause, or a community initiative might at first look like disorder, and sensemaking as a methodology allows one to sort out how to proceed in a convening in which anything might happen. As Allan Watts (2017) said, "That is what a master is looking for in a work of art: the optimal combination of order and randomness" (para. 1). Perhaps the greatest surprise in the inclusion of people who

have been labelled as having an intellectual disability is the discernment they themselves bring to these events—their certainty about what they want and do not want, their experiential learning and the logic that they make evident.

It is apparent in so many of our social endeavours that change must occur for various reasons—ethics, sustainability, practicality —and, as Judith Snow once wrote, "I have an intuitive grasp on a possibility that inclusion can lead to transformation in social and economic relationships." Many people with ID are leaders I willingly follow. The question is how to involve them in these larger conversations. Planning and dialogic processes related to person-centred planning's more familiar processes have the capacity to turn Snow's (2015) intuitive sense into reality, creating the potential for transformation of all kinds. It is relatively easy to use processes related to person-centred planning to create lively, transformational conversations about social change in local communities with mixed groups of people with and without disabilities.

References

Ancona, D. (2012). Sensemaking: Framing and Acting in the Unknown. In S. Snook, N. Nohria, & R. Khurana (Eds.), *The handbook for teaching leadership: Knowing, doing and being* (pp. 3–19). Thousand Oaks, CA: Sage.

Ashoka Foundation. (n.d.). *B.C. ideas: Solutions for stronger communities*. Retrieved from https://www.changemakers.com/bc-ideas-solutions-stronger-communities

Becker, C., & Pallin, R. (2001). *Person-centred planning approaches: A literature review*. Retrieved from http://www.qamtraining.net/docs/english/Person-Centered%20Planning%20Approaches.pdf

Berry, W. (2002). *The art of the commonplace: The Agrarian essays*. Berkley, CA: Counterpoint.

Block, P. (2008). *Community: The structure of belonging*. San Francisco, CA: Berrett-Koehler.

Burr, V. (2003). *Social constructionism* [Electronic version]. Retrieved from https://www.amazon.com/Social-Constructionism-Vivien-Burr-ebook/dp/B00VX8XHQC/ref=sr_1_1?s=digital-text&ie=UTF8&qid=1500834625&sr=1-1&keywords=burr+Social+constructionism

Costello, E. (1981). From a whisper to a scream [Recorded by Elvis Costello and the Attractions]. On *Trust* [Record Album]. New York, NY: Columbia Records.

Cummins, R. A., & Lau, A. L. D. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 16*(2), 145–157. doi:10.1046/j.1468-3148.2003.00157.x

Florida, R., Mellander, C. P. A., & Stolarick, K. M. (2010). Talent, technology and tolerance in Canadian regional development. *The Canadian Geographer, 54*(3), 277–304. doi:10.1111/j.1541-0064.2009.00293.x

Friedman, M., & Beckwith, R.-M. (2014). *Easy read results of the national study on supporting people with complex needs in leadership roles*. Retrieved from http://www.beyondtokenism.com/easy-read-results-of-the-national-study-on-supporting-people-with-complex-needs-in-leadership-roles/

Gatt-Fly. (1996). *Ah-hah*! *A new approach to popular education* (2nd ed.). Toronto, Canada: Between the Lines.

Gergen, K. J. (2009). *Relational being: Beyond self and community*. Oxford University Press.

Goodley, D. (2000). Self-advocacy in the lives of people with learning difficulties. Buckingham, United Kingdom: Open University Press.

Goodley, D. (2005). Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities, 9*, 333–343. doi:10.1177/1744629505059267

Inclusion International. (2011). *Inclusion around the world*. Retrieved from http://inclusion-international.org/wp-content/uploads/2013/07/IInewsletter-September.pdf

Johannes, A. (2013a). *People with intellectual disabilities as leaders: Collaboratively identifying strategies for success, using graphic facilitation* (Master's thesis). Athabasca University, Canada.

Johannes, A. (2013b). *Vernon inclusive research community mapping project journal*. Retrieved from https://101friends.wordpress.com/2013/03/20/community-mapping-project-journalmarch/

Johannes, A. (2016). Sensemaking through arts-infused person-centred planning processes. In B. Agerbeck, K. Bird, S. Bradd, & J. Shepherd (Eds.), *Drawn together through visual practice* (pp. 63–74). Seattle, WA: Amazon.

Johannes, A. (2017). *Alternative frameworks of sense*. Unpublished manuscript.

Kendrick, M. (2012). *Letting in the light: Reflections on leadership, ethics and human services*. Brisbane, Australia: CRU Publications.

Kilbane, H. S. (1999). *Person centred planning – a resource guide.* Retrieved from http://pathwaysassociates.co.uk/Archive/pdfs/pcp.pdf

Kitchin, R. (2000). The researched opinions on research: Disabled people and disability research. *Disability & Society, 15*(1), 25–47. doi:10.1080/09687590025757

Kunick, L. (2007, October 18). *Leaders with developmental disabilities in the self-advocacy movement* (J. Caldwell, Interviewer). Retrieved from http://digitalassets.lib.berkeley.edu/roho/ucb/text/kunick_linda.pdf

Masny, D. (2013). Rhizoanalytic pathways in qualitative research. *Qualitative Inquiry, 19*(5), 339–348. doi:10.1177/1077800413479559

McKnight, J., & Block, P. (2012). *The abundant community: Awakening the power of families and neighborhoods*. San Francisco, CA: Berrett-Koehler.

Merkley, C. (2007, July 24). *Mural on history of graphic facilitation/recording field.* Retrieved from http://www.shift-it-coach.com/2007/07/mural-on-history-of-graphic-facilitation-recording-fields/

Michell, B. (2012). Checking up on Des: My life my choice’s research into annual health checks for people with learning disabilities in Oxfordshire. *British Journal of Learning Disabilities, 40*(2), 152–161. doi:10.1111/j.1468-3156.2012.00742.x

Moore, S. (2016). *One without the other: Stories of unity through diversity and inclusion* [Electronic version]. Retrieved from https://www.amazon.ca/One-Without-Other-Diversity-Inclusion/dp/1553796586

Moureau, J. (2013, October 18). BACI maps “sweet spots” in Burnaby: Project identifies places in the community where people with disabilities feel welcome. *Burnaby Now*. Retrieved from http://www.burnabynow.com/community/baci-maps-sweet-spots-in-burnaby-1.664302#sthash.xEiph3KS.dpuf

O'Brien, C. L., & O'Brien, J. (2000). *The origins of person-centered planning: A Community of practice perspective.* Retrieved from http://files.eric.ed.gov /fulltext/ED456599.pdf

O'Brien, J. (1989). *Action for inclusion: How to improve schools by welcoming children with special needs into regular classrooms*. Retrieved from http://files.eric.ed.gov/fulltext/ED358672.pdf

O'Brien, J., & Lovett, H. (1992). *Finding a way toward everyday lives the contribution of person centered planning.* Harrisburg, PA: Pennsylvania Office of Mental Retardation.

O'Brien, J., & Towell, D. (2003). *Person centred planning in it's strategic context: Towards a framework for reflection-in-action*. Retrieved from http://www.inclusion.com/downloads/obrienarchive/Person%20Centered%20Work/Cranfield%20I.pdf

Patty, S. (2013). *Getting to what matters: How to design and develop evaluation* [Electronic version]. Retrieved from https://www.amazon.ca/Getting-What-Matters-Develop-Evaluation/dp/0985297131

Pitonyak, D. (n.d.). *Who holds your story?* Retrieved from http://www.dimagine.com/WhoHoldsYourStory.pdf

Roets, G. (2008). *Connecting activism with academia: A postmodernist feminist perspective in disability studies* (Doctoral dissertation, Ghent University). Retrieved from https://biblio.ugent.be/publication/4167118

Sanderson, H. (2000). *Person-centred planning: key features and approaches.* Retrieved from http://www.familiesleadingplanning.co.uk/documents/pcp%20key%20features%20and%20styles.pdf

Saul, J. R. (2005, August 1). His Excellency John Ralston Saul: "A circle of friends": Foreword to the publication in the company of others by PLAN (Planned Lifetime Advocacy Network). Retrieved from http://archive.gg.ca/media/doc.asp?lang=e&DocI.D.=4533

Shevin, M. (2002). Communication ally: The "missing-link" in PCP. Reflections on how people with communication impairments can take part in their own planning. In J. O'Brien, & C. L. O'Brien (Eds.), *Implementing Person-centered planning: Voices of experience* (pp. 197–214). Toronto, Canada: Inclusion Press.

Snow, J. (2015). *Great questions: Writings of Judith Snow* [Electronic version]. Toronto, Canada: Inclusion Press. Retrieved from http://www.inclusion.com/booksJudithSnow.html

Spectrum Consulting. (2014). *Cheryl's star raft salons 2013–14*. Vancouver, Canada: Spectrum Press.

Stainton, T. (2005). Empowerment and the architecture of rights based social policy. *Journal of Intellectual Disabilities, 9*(4), 289–298. doi:10.1177/1744629505059266

Steere, D. E., Gregory, S. P., Heiny, R. W., & Butterworth, J. (1995). Lifestyle planning: Considerations for use with people with disabilities. *Rehabilitation Counseling Bulletin, 38*(3), 207–223.

United Nations. (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-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

Vatland, C., Strickland-Cohen, K., Loman, S., Doren, B., Horner, R., & Walker, H. (2011). *Promoting self-determination for adults: A practice guide*. Retrieved from http://ngsd.org/sites/default/files/promoting_self-determination_for_adults_a_practice_guide.pdf

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures* [Electronic version]. Retrieved from https://www.amazon.ca/Inclusive-Research-People-Learning-Disabilities/dp/1843100614

Watts, A. (2017, July 3). That is what a master is looking for in a work of art: the optimal combination of order and randomness [Twitter moment]. Retrieved from https://twitter.com/AlanWattsDaily/status/882040792621121536

Wehmeyer, M. L. (1999). A functional model of self-determination: Describing development and implementing instruction. Focus Autism Other Developmental Disabilities, *14*(1), 53–61. doi:10.1177/108835769901400107

Wehmeyer, M. L. (2013). *The story of intellectual disability: An evolution of meaning, understanding, and public perception.* Baltimore, MD: Paul Brookes.

Wehmeyer, M. L., & Abery, B. H. (2013). Self-determination and choice. *Intellectual and Developmental Disabilities, 51*(5), 399–411. doi:10.1352/1934-9556-51.5.399

Wehmeyer, M. L., Bersani, H., & Gagne, R. (2000). Riding the third wave: Self-determination and self-advocacy in the 21st century. In M. L. Wehmeyer, & J. Paton (Eds.), *Mental retardation in the 21st century* (pp. 106–151). Austin, TX: Pro-Ed.

Wehmeyer, M. L., & Laurence, M. (1995). Whose future is it anyway? Promoting student involvement in transition planning. *Career Development for Exceptional Individuals, 18*(2)*,* 69–83. doi:10.1177/088572889501800202

Weiner, E. (2016). *The geography of genius: A search for the world's most creative places from ancient Athens to Silicon Valley.* New York, NY: Simon and Schuster.

Wetherow, D., & Fryfield, C. (2013, October 27). *Cheryl's star raft salon – a presentation.* Retrieved from https://101friends.wordpress.com/2013/10/27/cheryls-star-raft-salon-a-presentation-by-david-wetherow-and-cheryl-fryfield/

Wetherow, D., & Wetherow, F. (2016). *About the star raft*. Retrieved from http://thestarraft.com/

Whiteside, A. (2017, February 4). January brings the snow, makes your feet and fingers glow [Web log post]. Retrieved from https://alan-whiteside.com/2017/02/04/january-brings-the-snow-makes-your-feet-and-fingers-glow/

Worrell, B. (1988). Advice for advisors: People first. Downsview, Canada: G Allan Roeher Inst Kinsman.

"The individual must be the agent of his own education. He cannot be its object. That is why no one educates anyone." — Paolo Freire

"Live a charm life. Why? Because you can." — Liz Etmanski

Chapter 4:

The Nearly Lost History of the Lower Mainland Community-Based Services Society: A Successful Self-Advocate Initiative

Abstract

The Lower Mainland Community-Based Services Society (LMCBSS) was a successful non-profit service providing agency created in 1988 by those who had been labelled as intellectually disabled to serve their peers. It may have been the first agency of its kind in the world. By 1998, when the society disincorporated, it supported approximately 30 people in individualized residential placements, innovative day programs, a supported work program accessible to all, and led educational projects for their peers in leadership, sexuality, and self-determination. One of the last projects of the LMCBSS leaders was an affordable housing project, which essentially made them local leaders in community housing development (LMCBSS, 1996). As an organization, it was informed by an emancipatory rather than service-oriented framework. As a service-providing partner, LMCBSS was an equal among provincial agency and government leaders, which was new territory for self-advocates. LMCBSS was used several times in community conversations as an example of successful, satisfying leadership experiences, but always with the provision that they were still unsure why it had shut down. Early scoping investigations found no records of LMCBSS in the expected archival sources. It had been enfolded with several other small agencies into a larger whole in what was presented to self-advocates as a proactive response to a governmental agenda to increase efficiency by reducing the number of contractors. Two decades later, self-advocates who were board members of LMCBSS asked to share their oral history have it recorded. The resulting research examines how the society was formed and how it worked, and what the implications of recording LMCBSS's history through a social constructionist lens might be for future practices.

Relationship of this Research Article to the Dissertation

The research question addressed in this dissertation is what works to support the leadership of people with ID in their lives, groups and communities. Self-advocates in community conversations in different cities told stories of successful and satisfying leadership experiences, but the most frequently told local stories had to do with the LMCBSS It was decided to research and perhaps record it as a simple example of self-

advocate leadership, but as we further investigated, we realized that for local self-advocates there were still haunting questions about what had happened and why it had ended. Further, there was no information about the society in any of the expected sources. It seemed important to create a record for the self-advocates who had been involved, and also for the purposes of this research to document what had worked and allowed them to accomplish this singular feat. A focus group of former board members met over 2 days and we recorded the story of LMCBSS There are many examples in this local history of what worked to support them, but it also raised many questions. As with the other parts of this research graphic recording allowed a holistic sense of the conversation.

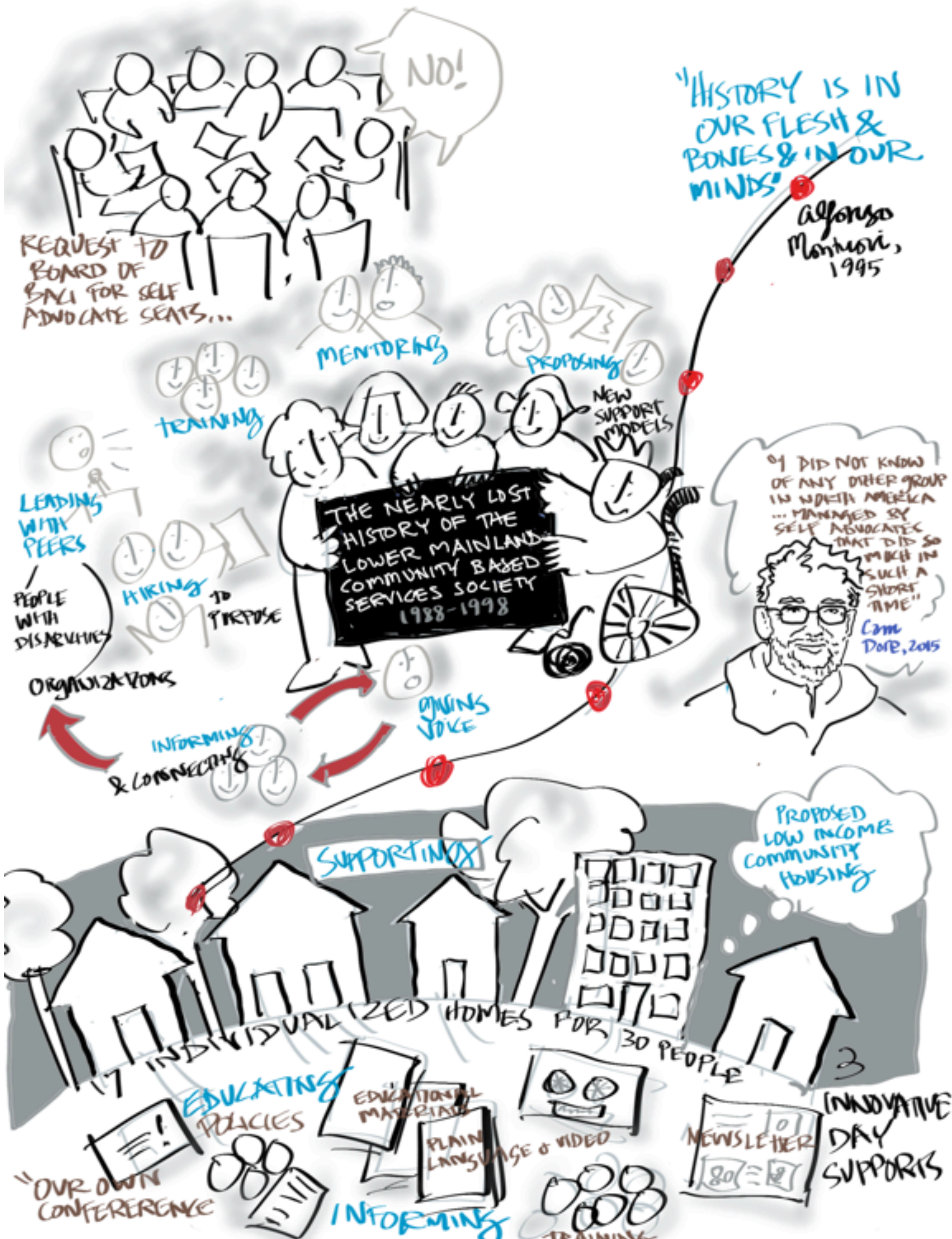


Figure 24. Relationship of this research article to the dissertation, graphic

"I'm just sorry I don't have all the papers – that would be helpful. But I waited seventeen years for someone to ask about this." Research participant.

Introduction

During a series of community conversations with people with ID about leadership (Johannes, 2017), older, local participants frequently used the LMCBSS as an example of successful, satisfying leadership. LMCBSS was a non-profit service providing agency formed and led by self-advocates from 1988–1998. Younger participants had not heard about LMCBSS but were very interested.

LMCBSS was one of many small organizations set up in response to the de-institutionalization of the province. In some of the new agencies, staff from the institutions managed or worked with those they had supported institutionally (E. Baatz, personal communication, December 10, 2016), and people's lives did not hugely change, whereas some new organizations conceived of different kinds of approaches and offered alternative supports.

This social constructionist approach to the co-creation of research data took the form of stories, narratives and graphics collected in informal "community conversations" with groups of self-advocates. Two social problems addressed in a larger research project that this is part of, were that people with ID have limited opportunities to lead, and that their leadership activities are either unrecognized or perceived as exceptional rather than as proven, demonstrable skills of an identified subculture. For people with intellectual disabilities, what Hagel (2013) has called "the pull of narrative . . . [that has a] persistent context" (para. 1–3) is almost always provided by those who support them. Often, it is not them who "holds . . . [their] story" (Pitonyak, n.d., p. 1).

It became apparent that the story of the leadership of LMCBSS would be a suitable example of themes of the larger research project, and it was also important in this collaborative research to respond to the requests of the self-advocate co-researchers. The ideal of inclusive/emancipatory research "is that disabled people are in control—of the funding, the methodology, the questions, the analysis, the dissemination" (Walmsley, 2001, p. 198). In terms of social constructionist research,

such collaborative dialogues allow us to make meaning together out of what had, it seemed, ended mysteriously and painfully (McNamee, 2010). In the process of learning about research themselves, advisors with ID suggested that for the kind of "future forming" (Gergen, 2015, p. 287) conversations research might make possible, they must know foundational parts of their own local leadership history.

They listed several reasons to debrief the history of LMCBSS:

- LMCBSS's activities ended without resolution for them.
- They wondered if LMCBSS closed down because they had done something wrong, and if so, what needed correction?
- Elder advisors wanted this story of their work to contribute to the history of the self-advocacy movement, and younger advisors wanted to learn from this unheard story.
- They wanted to understand how and why parts of their history went missing.
- Understanding how leadership at LMCBSS worked would provide good information about how self-advocate leadership worked, which would inform the research we were doing together.
- They wondered if this might be a better time for a similar self-advocate directed service providing agency (or some similar influential project).

This research presents the self-advocate narrative of their work in their own voices as a chronological overview of the history of LMCBSS, contextualizing it within the local history of disability supports and the self-advocate movement (local, provincial, and national).

Historical Overview

There is a continuum of related but different stories about how LMCBSS started. In one, local leaders were motivated by a presentation on self-advocacy by People First of Canada (Reimer, 1996). In another, in 1987 self-advocates requested seats on the board of an influential local service provider in Greater Vancouver, and were refused (C. Dore, personal communication, January 12, 2015). In a variant oral history from a participant, a government project sought to fund and support new self-advocate

initiatives. In any case, allies without disabilities who understood organizational non-profit development assisted them, and in 1988 the Constitution of LMCBSS was registered and incorporated on July 21st by the British Columbia Registrar of Societies (LMCBSS, 1988).

A year later, LMCBSS opened the first of what would become approximately 14 homes. Their interest was in individualized smaller residences created for specific persons, rather than traditional group homes. Residential services were complemented by at least three different community-based day support models and an employment program to give a range of choices as an alternative to the more typical sheltered work and segregated recreation programs of the larger, older agencies. By 1997, LMCBSS was not only supporting peers with ID but also developing a new housing project to serve 40 low-income families, effectively becoming a local leader in accessible housing. LMCBSS also hosted strategic projects to create and distribute informational materials about self-advocate leadership and topical themes, such as “Independent Living: Marriage and Family” (LMCBSS, 1996; Reimer, 1996).

In 1998, in what was explained as a proactive response to the government's intention to restructure contracts to form larger organizations, LMCBSS merged with three other community living societies under the new name of Mainstream Association for Proactive Community Living, later known as simply Mainstream and then re-branded as posAbilities. Other small agencies at the time also amalgamated to form larger organizations, while others continued on course, offering a range of person-centred alternatives (E. Baatz, personal communication, December 10, 2016; S. Mahar, personal communication, December 5, 2016).

Participant Selection

A snowball sampling methodology (Handcock & Gile, 2011) was used to allow core participants to decide who should be part of the discussion, with the founding President of the LMCBSS board making initial invitations to stakeholders who were then asked to suggest others to invite. Deciding who to involve was taken very seriously in the creation of a list of about 15 potential participants. There was discussion about

whether to invite former staff and stakeholders of LMCBSS (people without disabilities). Some tentative invitations were made, but as these were not readily accepted, former self-advocate board members decided to proceed on their own.

In the end, seven self-advocate participants, three women and four men, ranging from 30 to 65, attended a first focus group. On the second day, five of these attended, as well as two younger self-advocates who had expressed interest. The older self-advocates thought their questions might be generative. Two other former board members accepted invitations but were unable to attend at because of health issues. Thus, nine of the 11 people invited were able to participate.

Methodology

The question of this inclusive research was how LMCBSS was started, what it did, and how it ended. Secondary research questions had to do with what LMCBSS meant to the self-advocate leaders involved in it, and whether such an initiative could occur again. The overarching theoretical underpinning of inclusive research has been well presented in such projects as *It's Our Lives: A Short Theory of Knowledge, Distance and Experience*: "The greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted" (Beresford, 2003, p. 4). For the comfort of participants, discussions were also co-facilitated with a self-advocate leader (Caldwell, 2013; Caldwell & Nellis, 2014) and graphically recorded by a self-advocate artist with support.

Social constructionist research, which prioritizes the relationships of researchers and subjects, is made up of methods focused on how meaning is co-created (McNamee, 2010), in this case within the interactions of the original LMCBSS members. This was accomplished through the use of a collaborative framework, which consisted of four parts:

- initial exploratory questions, which were sent out to a broad range of people and organizations in hopes of collecting primary LMCBSS documents, or memories of their work;
- a story-based focus group discussion with former board members;

- analysis of the data as a chronological narrative in the context of its time; and
- the iterative return of the research to the self-advocate community in accessible forms such as graphics, dialogues, workshops and co-facilitated events, which led to further discussions (Barnes, 2002; Caldwell, 2013).

A collaborative research framework "refers to partnerships or collaborations in which people with and without disabilities who work together have both shared and distinct purposes which are given similar attention and make contributions that are equally valued" (Bigby, Frawley, & Ramcharan, 2014). The researcher brought to the project an understanding of how data can be collected, facilitation processes, and academic procedures; the research project advisory group and the participants thought critically about their roles and the role of LMCBSS in self- advocate history, brought remarkable organizational and personal memories, particularly when facilitated to remember together in a dialogue; graphic recorders brought the ability to draw their memories and allow them build on their discussion (Johannes, 2013).

These combined strengths allowed for the interweaving of data from the remembered stories of stakeholders with primary historical documents, memories from former staff and colleagues, other agencies, and governmental sources to create a kind of assembly of truths. In modernist research traditions there is a sense that an objective reality exists to be deconstructed and determined, if only we can be distant enough (often, from what we care deeply about) we can find out what the "truth" is. McNamee (2010) has said social constructionism incorporates some key themes such as a concern for processes, communication as generative, the co-construction of "relational realities" (p. 11) and what people do, or may do, together, to create the world they aspire to.

A chronological history was created from the memories of those who had been involved. These stories were recorded graphically to support participants' involvement in complex conversations (Johannes, 2013, 2016; Mullen, 2013; Mullen & Thompson, 2013). The emerging graphic allowed participants to feel heard, and as a group to expand on their accruing collective memories, as well as for member checking. Notes were also taken and sessions were audiotaped and transcribed for accuracy.

Relevant Literature Search

A literature search provided no information about LMCBSS or other similar support-providing organizations created by and for people with intellectual disabilities. While some documentation of client-led and directed support services identified "mentally disabled" persons (e.g., Sega, Silverman, & Temkin, 1996) these were about people labelled through psychiatric interventions, and not about people labelled with ID. However, a growing number of resources are available to critically examine self-advocacy over the lifespan (Goodley, 1997): self-determination (Wehmeyer, 1999; Wehmeyer & Abery, 2013; Wehmeyer & Laurence, 1995), self-actualization (Beresford, 2003; Snow, 1994), the support of inclusion by allies, organizations, and government (O'Brien & O'Brien, 2000; Worrell, 1988), and the absence and inclusion of people with ID on boards (e.g., Bates & Davis, 2004; Craig & Bigby, 2015; Drake, 1992, 1994, 1996; Frawley & Bigby, 2011; Mittler, 2008; Saidel, 1998), and this research is informed and contextualized by these authors.

However, even the most positive authorities appear to view self-advocates in supportive, contributory roles rather than as a directing force (Wehmeyer, Bersani, & Gagne, 2000, p. 112). For example, the largest recent study of self-advocate membership on leadership teams in the U.S., the "Beyond Tokenism" project, presents questions and instruments about people with disabilities serving as authentic, valued advisors and contributors, but not as organizational leaders (Friedman & Beckwith, 2013).

Primary Documents

Board members remembered that LMCBSS created all the requisite manuals expected of any non-profit service provider of the time, on various topics for employees, people served, board members and funders. These included policy and board manuals required for governance, and operational documents related to bidding, negotiating and being contracted to provide services. As well, LMCBSS created informational materials in the forms of plain language booklets, pamphlets, and videos for those they served and for their peers in the community. When these were unavailable in collections, requests

to borrow copies, or even of memories of them, were widely distributed (M. Feduck & K. DeLong, personal communication, January 5, 2015), and the organizations where they might be expected to reside were followed up with. However, only two redacted documents were received from the archives of the larger agency that LMCBSS's holdings had been incorporated in.

A founding member of the LMCBSS board later discovered a storage box of materials and a copy of the Certificate of Incorporation (LMCBSS, 1998). Inquiries to the Charities Directorate, Canada Revenue Agency brought records of financial statements in which LMCBSS's income was found to be $21,997 in 1991 (the earliest year on record), growing to by 1998 to $3,429,280 (S. Descary, personal communication July 22, 2016). The posAbilities Society, the agency formed out of LMCBSS and other small agencies, very recently published an informal commemorative history of their organization, which includes a section on LMCBSS's foundational role (posAbilities, 2015). During the actual focus group meetings, participants also brought three VHS videos made by the agency that were digitalized.

In total approximately 200 pages of primary sources and three videos were eventually discovered (see Appendix A). These pages refer to others that have not been found; for example, the Policies and Procedures Manual index seems to go up to page 607 but only about 150 pages were found.

These differ from similar agency documents in the assumptions of relationship between self-advocate leaders and stakeholders. For example, the LMCBSS *Policy and Procedures* manual for new staff begins with a letter from the founding President, which promotes relational expectations and values:

> *I am happy to have you join LMCBSS You are part of a unique society. LMCBSS was created by a group of self-advocates and other people who wanted to give a second chance to people who are labelled handicapped.*
>
> *We have hired you because we feel you want to be involved with self-advocates in the houses and with the Board. . . .*
>
> *I am glad that you are beginning what will become, I hope, a rewarding experience for you and for all who are involved.* (Goode, as cited in LMCBSS, 1989, p. 708)

Each policy in the manual begins with a philosophical statement of intent. Policy 207, for example, is on having friends:

> *LMCBSS values the essential roles that friends and advocates play in the lives of people with disabilities. These roles include:*
>
> - *Providing support, love, caring and understanding*
> - *Providing a person with unconditional acceptance*
> - *Promotion of self-esteem through:*
>   - *the provision of a sense of connection to the larger community and*
>   - *the value of being cared for by someone who is not paid to care*
> - *Acting as advocates whose prime interest is the person whom we serve*
> - *Acting as an additional monitoring agent.* (LMCBSS, 1989, p. 208)

It goes on to extensively encourage the procedures and practices of "participation of all friends and advocates in the lives of those people we support" (LMCBSS, 1989, p. 209) who are welcome to visit at any time, with staff having responsibility to keep them aware of events, issues and concerns, and include them in planning.

We can compare this in tone and intent to a policy for another British Columbia agency found at random on Google, which seems more typical:

> *PREAMBLE*
>
> *Pathways Abilities Society recognizes and acknowledges licensing requirements and in so doing, recognizes the Person In Charge (supervisor) and his/her designates as the primary caregivers who are responsible for the health, safety and well being of each individual residing in a licensed care facility.*
>
> *POLICY*
>
> *Pathways Abilities Society ensures the health, safety and well being of the residents by teaching and assisting them to make informed choices in their home and community to promote opportunities for positive, safe interactions.*
>
> *Residents have the right to have visitors and guests providing they do not compromise the health, safety and well being of the other residents.*

> *With their permission or on their behalf, residential staff will facilitate and encourage communications between residents, their friends and family when arranging social outings while at all times honouring the wishes of the residents.*
>
> *Parents, siblings and close friends do not require a criminal records check prior to accessing the community with the residents. Anyone unfamiliar to the individual, their family or advocate, must have a criminal record check completed unless Pathways Abilities Society staff are present during the outing.*
>
> *In compliance with Residential Care Regulations, if staff has reason to believe a resident's safety is at risk by leaving the facility with a family member or friend the resident will not be permitted to leave. . . .* (Pathways Abilities Society, 2015, p. 1)

The differences in the two policies are evident, the one focused on valuing relationships, the other on satisfying bureaucratic requirements relationships might make necessary.

While the above policy is notably more restrictive, it at least recognizes that people might have friends and relationships. Actual practices, fuelled by restrictive policies, can be much worse. Pat Fratengelo tells the story of trying to reconnect with Michael, someone she had known for 18 years, served by an agency she was once employed by:

> *Within seconds a staff member came over and told me that I could not take Michael anywhere. She said that she did not know me and said aloud to Michael and me that 'he picks bad people to be friends with.' I told her Michael and I have known each other for probably 18 years and that we reconnected at a wedding this summer and had been in contact back and forth since that time. She again said that Michael could go nowhere with me. . . .*
>
> *The bigger questions really were; why can he meet me alone somewhere but I cannot go into his home; and why can he meet me somewhere but not travel with me to the same location? What really was the rule behind on our seeing each other? The staff firmly said that Michael could not ride in my car. She had checked with the "office" and I was not approved to take Michael anywhere as I was not on his "visitors list."*
>
> *I had never heard of a "visitors list" and questioned her on what that was. She barked back at me and said "everyone in the agency has one and no one can take anyone out unless they are approved!" She said that I would need approval and also need to sign in and out to see Michael or anyone in the agency. I felt like I was talking with the Gestapo!* (Fratengelo, n.d., para. 4–6)

Throughout, LMCBSS documents imagined a least restrictive environment and presumed competence, with “just enough” support for specific situations. In all cases, decision making was seen as their right, and the work of the agency’s employees was to support them in this.

Focus Group Discussions

Figure 25. Graphic, focus group discussion.

A chronological examination of events before, during and after LMCBSS operations allowed participants to remember together and gradually co-create a picture, literally, of their history (see Figure 25). Both sessions began with a member generated discussion of confidentiality and participants decided in the moment that their contributions would be anonymous, to encourage speaking freely. They came to agreements about letting each other finish their sentences without interruption and not correcting those who might remember things differently. One stated, “Can I just say – a lot of things are going on in my mind but . . . for me, some memories might be different, everybody's memories might be different and that's okay.” As they talked and listened to each other, and were reassured their memories resonated for others, the group moved through the remembered history of LMCBSS with increasing confidence.

While grateful for the opportunity to debrief LMCBSS there was a sense of particular loss about documents that might have been useful, and a carefulness about the responsibility of memories:

> *"I agree with you guys . . . [that we might remember things differently]. That's important. . . . I could have brought some papers down. Maybe those papers would have been part of the discussion. . . . I had boxes of stuff . . . but I had to get rid of them a couple of years ago. I didn't know. I'll do my best. I'll do my best, but you'll have to guide me sometimes."*
>
> *"But you might remember something I don't."*
>
> *"That's true."*

Participants began by remembering LMCBSS-related events in connection to landmark moments in Canadian self-advocate history which they had been part of:

> *"We had meetings and training from People First of Canada by people like Peter Park and Bill Worrell from Ontario."*
>
> *"[After that] there were many local groups and provincial groups."*

When some participants forgot details, others remembered:

> *"We [self-advocacy group] used to meet at Woodlands [British Columbia's largest institution, still open at the time]."*
>
> *"It was weird – why did we meet there?"*
>
> *"Because the local agencies were not interested in hosting us."*

Their understanding of the subtleties of how systems worked and self-advocates were tokenized was telling:

> *"Back then it [the provincial umbrella of service agencies] was the B.C. Association for the Mentally Retarded – B.C.A.M.R. – they didn't want to change their name."*
>
> *"Then they started the Self-Advocate Caucus – it was run by the Self-Advocate Foundation and had an advisor – they elected two people to go to the B.C.A.C.L. [British Columbia association for community Living] board meetings, but they didn't get a vote."*
>
> *"A voice but no vote! Remember that?"*

Starting up LMCBSS was full of opportunities to learn and grow, and test theories of self-determination. This occurred in relational ways:

> *"It was a long hard process. With a lot of help we did it."*

"It was fascinating to see if I could learn something – I had never been part of anything like this in my life."

"I learned a lot of stuff that first year. It was amazing, and then I stayed involved. It was nice to be connected to other people who were leading – [we] managed to stick together for years, it was nice –"

Self-advocates remembered LMCBSS being a significant sign of change:

"Self-advocates had never run an association before."

"We went from service recipients to consumer groups to self-advocates. And then we were employers."

Self-advocate board members took on a variety of strategic roles at LMCBSS, ranging from legal signing authority to staff hiring and training:

"As I remember it I think that we – . . . we signed lawyer papers, different kinds of papers."

"No one ever asked about us signing the contracts – but until we did it no one thought we could."

"We got to replace the Executive Directors and the staff when it was time to do that."

"We trained new staff about what we expected from them."

They also took on operational and managerial roles as they supported the transitions and return of people with ID from institutions into their communities:

"We went and checked out things [in the homes] on a daily basis."

"We went to visit people from Glendale [a British Columbian institution for people with intellectual disabilities specializing in complex care] to pick them up and move them to [new homes in] Burnaby."

"We even took a couple of people from Woodlands – we welcomed them to new lives."

LMCBSS directors were responsible for several innovations, such as supported employment and housing:

"We thought people should have a chance to get jobs so we had an employment service to help . . . all kinds of people."

"We were trying to make the housing different – not groups homes for 4 or 5 people but like a fourplex – 2 people in each half of a duplex."

Participants saw the idea of innovation as an intrinsic part of what they offered as a group of new and different leaders:

"I think it was an innovative move that the society [LMCBSS] we belonged to . . . they were innovative . . . it was a place that self-advocates could call home."

"I was part of it for slightly over 10 years. We had our own newsletter. We hosted a conference."

"I forgot we had that conference!"

A perhaps unexpected result of creating and leading an agency was that the self-advocate directors represented LMCBSS as an equal within a growing body of post-institutional provincial agency leaders:

"We got to be members . . . at the provincial level – we did that every year [went to the A.G.M. [Annual General Meeting] of the provincial umbrella society] and were able to vote on provincial issues about disability related things."

This strategic vantage point also gave them the opportunity to inform and educate their peers:

"I wanted to learn, I wanted to report on what I learned . . . the importance of [being able to give] input, of understanding what we need to work on, of supporting people to do the best they can by doing the best we can."

"I was doing a lot of reporting [about LMCBSS] to the Self-Advocacy caucus – reporting on the downsizing of Woodlands – and with Burnaby People First, and to the associations. I went to conferences and attended workshops and tried to share what I learned."

One of the achievements of LMCBSS was the utilization of different grants to hire summer students for projects. For most agencies, such students would have assisted regular staff to support leisure and recreational activities such as outings and attending camps. Instead, LMCBSS board members led students in projects to create useful tools with and for those supported by the agency and their peers:

"I can remember when a group of us put together a plain language [document] about the disability pension – I feel like I've done a lot of things and for me to be

around even to talk about it – we can't forget it. It's something I am very proud of, to be able to share it with other people."

[Shows three VHS tapes that were LMCBSS projects] "These are 'Speaking for Ourselves,' about self-advocate leadership; 'Living with Choices,' about how to make decisions, and 'Saying No: videos about sexual abuse prevention.'"

While one focus was on informational documents, another was on how people might be supported in self-representation:

"The ministry asked you questions every year, where you lived, what you did [to qualify for supports and funding] – we wanted to make it easier for the staff to bring the people into the reviews [often done by parents or staff without the individuals] – [we wanted] plain language – we made some things to help (staff procedures? pamphlets?) – we wanted to make sure people got the services."

"Some people couldn't read; it was a new idea [for government workers] to read it to them."

Local projects gave LMCBSS leaders an opportunity to respond to national issues, such as the Eve case, in which for the first time people with ID were represented at the Supreme Court of Canada, where there was a decision that they had control over their bodies and could not be sterilized without consent:

"We need to help people remember the Eve case.[2] It was so important to us, then and now" (see Appendix B).

LMCBSS board members saw the local and personal implications of this federal case, and worked to create educational opportunities for those they supported and their peers:

"We were fighting for one woman's rights – but that made us think we had to fight to inform all people with disabilities."

"About sexual health – we needed to help people take responsibility – to make decisions that were informed – not just leaving it up to the parents."

---

[2] The Eve case was later brought up as another story that needed to be told before we could move into thinking about the future. This led to a series of conversations and, as it was the 30th anniversary of the Supreme Court decision, a graphic to be used in self-advocate workshops, a series of talks, videos and a website (Centre for Inclusion and Citizenship, University of British Columbia, n.d.).

> *"We had a committee all about reproduction – I remember it very fondly – people didn't think we could do things like that [to demonstrate that instead of being sterilized they could learn new skills and be educated in sexual decision making]."*

In their 8th year the directors began to think strategically about diversifying sources of funding to continue such projects independently, with or without government grants:

> *"I remember the Mardi Gras party."*

> *[That was the] "First fund raiser – around 96/98 and all of the sudden we were fundraising . . . we wanted other money for our projects, that we could control more."*

However, even in the midst of these new possibilities, LMCBSS was disincorporated in 1998.

Board members were initially approached about the idea of their society being folded in with other small agencies just before an upcoming annual general meeting (AGM). Their detailed memories indicate the importance of this:

> *"The E.D.'s [Executive Director's] new idea was to change the name, to get parents involved, to get other people involved . . . they didn't want self-advocates running the agency any more."*

> *"They changed the bylaws – the number of people with disabilities – so that some people with disabilities were still on the board."*

> *"He [the Executive Director] said we have something very important we want to talk to you about – it's going to be a special meeting – it'll be longer than we expected – he put the name change on the agenda and we just waited until we'd talked about the other items – you know how you always have an agenda."*

> *"[He said], 'How do you feel about what we do with our agency in the future. You've been great – you've been running this for 10 years.' He mentioned about the change. Can we make a resolution to have less self-advocates on the board. . . . He mentioned the new society name Mainstream – I think it was Mainstream."*

Participants understood the implications of what was at the time called the contract restructuring project, intended to reduce the number of small agencies government contracted with to create a more efficient system:

> *"The ministry was going through a lot of choices – at one time it was sink or swim – you kept going or you got swallowed up . . . we got approached by a number of agencies [to join with them], and Mainstream was one of them. They said 'You're just what we've been looking for,' so rather than fold, we amalgamated."*

Memories of the actual AGM differed from other topics in that participants were confused and emotional, nearly 20 years after the event. The decision to be part of the amalgamation was a difficult one, and not everyone was in agreement:

> *"Everyone agreed to do the change when we voted on it [at the AGM]. We thought we liked it at first and we didn't debate and we decided to have the members vote as well."*

> *"We were concerned we were losing all this power how will we do our annual reports and report back from conferences – lots of people were afraid and hadn't spoken up [earlier] – then someone spoke up. People did listen."*

> *"When it got to this part they [the members] put a special resolution on the floor and . . . we changed our mind and we reversed and we defeated the motion."*

After the motion to amalgamate had been passed, it was then reversed through a motion from the floor and another vote by members. The Executive Director responded,

> *"When the E.D. [Executive Director] said he was upset we had to put another motion on the floor to go back to the first motion . . ."*

> *"We had to revote – there were lots of people who could speak up . . . and then we had to have a special resolution to do it again, and we accepted that we would start a new named association."*

> *"This is hard . . . they took it over and then they went through two more name changes, it was a painful thing for me. This makes me think that I had a bunch of papers too . . . I could have brought the papers, but I got rid of boxes of papers a couple of years ago. No one seemed interested."*

In 1998, the charitable status of LMCBSS was revoked and their assets transferred to the new amalgamated society (Canada Revenue Agency, 2017). After the amalgamation, LMCBSS board members felt increasingly distanced and confused:

> *"We brought new people in – other people without disabilities. Some worked for other organizations as well, or their wives did."*

> *"They kept changing their [agency] names and [roles] then I forget [gets confused] about who was involved and who worked where."*

"We had a couple of years where we [self-advocates] were still running programs, but then things stopped."

"We tried to educate people – we hired summer students to help us with these projects. When we ended – I don't remember – we didn't really understand – in my mind we didn't really understand why we were closing down."

"People didn't really tell us. . . . I might be wrong but that's how I remember it . . . all of the sudden it finished and I didn't know why. Sometimes I think we shut down because there were other organizations that wanted to take over."

"We went from the B.C. Association for the Mentally Retarded Children to BCAMR B.C. Association for the Mentally Retarded to BCMHP – British Columbians for Mentally Handicapped People to BCACL British Columbia Association for Community Living to Inclusion B.C. and [locally] we went from the Lower Mainland Community-Based Services Society to being part of Mainstream Association for Proactive Community Living and then they went to posAbilities."

"It was very confusing about name changes."

"I do like those [later] names better."

As focus group participants remembered the events surrounding the disincorporation, and younger self-advocates asked questions of them, they were able to reflect more on what continued to concern them so many years later. A younger self-advocate noted that there were now many kinds of agencies and self-advocacy groups, so why had there been this pressure to become one larger organization:

"It was hard – . . . Looking back on it I think there are lots of different kinds of groups doing different kinds of things all over now and why can't people with disabilities have different groups too?"

"Do [all] those [service agencies and] groups clash? People have different truths – like we were saying – there can be small truths – we don't need to argue; there can be a large truth we agree on together, too."

A younger self-advocate stated,

"This reminds me of when I went to see concentration camps in Poland – the family was split into groups – I didn't know how to process it: that really happened?"

When asked how their involvement with LMCBSS changed their lives, participants said:

> *"I wouldn't get anywhere if I didn't show up. [LMBCSS gave me a way to show up]."*

> *"Before I didn't feel good about myself for a long time, but now I do."*

> *"People hear me, I learned how to be heard, how to speak out – [I was] talking to the parents at our [local agency's] AGM, and they said maybe my son or daughter could do this?"*

> *"I learned how to be a public speaker – how to talk about my life."*

Initially, participants' thought this research might lead to new ideas about how to organize a similar service providing society, but as the conversation continued this proved not to be the case:

> *"I feel too old to do this again."*

> *"I would bring in more fresh faces – we can't go back to do it ourselves anymore we're aging ourselves."*

> *"If they want to do it, one person, a time and not as a group – this work that we've been doing is not just individuals, and it's not even just one group it's all the groups and all the people who have had faith in us."*

> *"People just want to belong . . . they want to be involved because they want to be. . . . And maybe they [also] want to belong to their local association."*

> *[They generate a list of groups that are not affiliated with the self-advocacy movement per se which are part of agencies.] "I think as long as there are self-advocates on the board[s] [things are okay]."*

As we ended the session, participants discussed what had not changed since they started and ran LMCBSS:

> *"Associations pick up new ideas and see that as the first step in something new . . . [there were many steps before the ones they are taking now]."*

> *[I think about] "Tracy Latimer [a young disabled woman killed by her father who felt her quality of life was untenable] – I brought that up with our association – I was very emotional. When you hear about parents – this person [who] couldn't speak their mind and it ended tragically . . . people get sterilized – sad issues tragic issues – that we have to bring up sometimes."*

> *"I went to see Gilbert Grape [recently] and there were [similar] discussions [to those had when we started LMCBSS]. People still can't get a voice [in the agencies that support them] – they are still out there."*

> *"When people grab the microphone there's a reason for it – they feel safe and comfortable – they're getting to a place . . . they're being heard."*

Participants ended by discussing what the debrief had meant to them:

> *"This is very deep in my heart. I don't want to let this go."*

> *"We appreciate this opportunity to finally talk about what happened – I've always wanted to do this. Thank you."*

Discussion

While many organizations involved in deinstitutionalization took on, to greater or lesser degrees, institutional concepts in a kind of penumbra effect, LMCBSS demonstrated radically different intentions, which were operationalized in their supports. This led to an important sense of belonging, of "coming home" and being part of a family of choice. Peter Block, writing of how we might interact as communities of various kinds, focuses on this idea:

> *To belong is to know, even in the middle of the night, that I am among friends . . . Experiencing this kind of friendship, hospitality, conviviality is not easy or natural in the world we now live in. The second meaning of the word belong has to do with being an owner: Something belongs to me. To belong to a community is to act as a creator and co-owner of that community. What I consider mine I will build and nurture*. (Block, 2008, p. xii)

There is some disagreement on why and how LMCBSS was started. Cam Dore (2005), former Executive Director of the BAMH (Burnaby Association for Mentally Handicapped, later known as BACI, the Burnaby Association for Community Inclusion), writes:

> *LMCBSS grew out of the . . . failure to support Self-Advocates attempts to get on the BAMH board. The very conservative board in those days essentially told SelfAdvocates that they did not need to trouble themselves with board stuff that they would look after them . . . it took 5 or 6 attempts to even change the name of the society with much heart break along the way. . . . They also felt that Self-Advocates could not sign legal contracts.*

> *. . . I did not know of any other group in North America at the time, managed by Self-Advocates that did so much is such a short time.* (C. Dore, personal communication, January 12, 2015)

However, a later Executive Director of LMCBSS framed their conceptualization somewhat differently in "The History of LMCBSS," a more public document to be distributed at an AGM:

> *The Peoples First Group's presentation at the 1987 British Columbia Association for Community Living's annual general meeting was the inspiration behind LMCBSS From there LMCBSS was started with two objectives in mind. First was the integration into the community of people leaving institutions, mainly from Woodlands and Glendale. By supporting homes for people labeled with disabilities, LMCBSS has provided a welcome back for people returning to the community. The second objective was a strong commitment to the involvement of Self-Advocates in the decision making process with a service providing society. With this commitment, LMCBSS became the first service providing society in Canada whose Board of Directors was made up of a majority of Self-Advocates.* (Reimer, 1996, pp. 8–9)

In the most recent documentation of how LMCBSS came to be part of a larger organization, from a keepsake history created by them for a retiring board member, they state:

> *The merger was prompted by the agencies being small and scattered across a large geographic area. Although the range of programs they offered was impressive, the effectiveness of some programs operating as stand-alone services without tie-ins to other essential programs were not what they could be. The reach and impact of these smaller agencies as part of a larger more effective whole would be greater, and given the shared philosophy and values of the group, a merger was the next logical step.* (PosAbilities, 2016, para. 1)

Walmsley has suggested that the foundational focus of western civilization on the idea of citizenship as requiring logic is what undermines acceptance of self-advocates as equal citizens and supports the social construction of disability through deep seated historic and unquestioned assumptions about this lack of ability to "reason" (i.e., to be rational; Johnson, Walmsley, & Wolfe, 2010, pp. 32–35). The service delivery system created around people with disabilities is based on this assumption, thus always positing a discourse of inequity between those with labels and those without (Rapley, 2004).

However, LMCBSS instituted some ideas that would still be considered best practices. In their homes for people with behavioural challenges they contextualized behaviour as communication and focused on least intrusive supports, capacity building and the idea of the person served as the decision maker (LMCBSS, 1993). Discussing those with significant challenges, former board members were puzzled by the suggestion that anyone might be “too much” for them: these were their people, no matter what.

The self-advocate leaders created an infrastructure of requisite policies, procedures, contracts and obligatory documents and even built on this by creating instructive pamphlets, booklets, and videos, and yet most of these artifacts have been lost and almost none were in the archives one might expect to hold them. Importantly, LMCBSS followed the rules and policies of funders and government bodies in an exemplary way. They filed timely tax returns, followed through on their requirements as a non-profit and as employers and contractors, and bargained in good faith with successive partners. They dedicated time and energy to creating different kinds of documents for different groups of stakeholders. In short, they followed all the rules. Yet even so, they were unable, as Audre Lorde famously discussed, to use the tools of the master in his house (Lorde, 1979), the leaders of LMCBSS were, in the end, unable to participate as equals in leadership as they were pressured to amalgamate and, deciding not to go through with it, pressured more. Such stories made one think that the person responsible for this pressure was the “bad guy” in the story, but when I finally asked I was told that in fact he was the hero as he had been the person who helped them create the society in the beginning.

The history of the LMCBSS resonates with contemporary events. More recently, in British Columbia, a community-based provincial project to rethink supports for people with ID resulted in Community Living B.C. (CLBC), a new Crown corporation responsible for supports. The constitution of CLBC was always imagined as requiring the contributions of self-advocate board members, having three in its first iteration and after that a requirement of two (Crawford, 2004, p. 107). Self-advocates celebrated that

the government acknowledged that "people with developmental disabilities and their families . . . actually want some input in designing the services" (Fowlie, 2011).

However, in 2009, without warning or explanation the constitution was amended to no longer require their presence. This pattern evident in the story of LMCBSS of invitation, inclusion and then exclusion without explanation or debriefing through bureaucratic methods which Titchkosky (2011) says are so often used in dealing with people with disabilities as "a rationalized form of power accomplished and enforced through procedural requirements seemingly impervious to the particularity of unique or individual desires" (p. 8). Soon after, Community Living B.C. was deemed to be in crisis due to "a loss of the compass of human services . . . that we always have the people in the room for whom these decisions impact the most" (Fowlie, 2011). Titchkosky has found this pattern so prevalent in the way culture deals with disability that she has termed it "always-absent-presence" (p. 90):

> *At the edges of this boundary [between disability and normalcy] resides the possibility of defining and shoring up belonging and not belonging, relevancy and irrelevancy, personhood and its Other. Disability, in this instance, can be characterized as the abject underside of legitimated existence, included as an excludable type by signifying it as an always-absent-presence. As a living paradox, the place where we do and do not find ourselves, where people do and do not represent the issue of disability, is intimately connected to a historical set of questions regarding the meaning of being human.* (p. 90)

Leadership can be a useful lens on how people access their rights. In the area of critical disability studies it allows us vantage points of various kinds. These range from those who have said their experience was that someone with ID might have to work relentlessly to be able to make choices on a continuum from the smallest to the largest aspects of their lives: to "lead" their lives, to those who can compel a mass of people from a podium. In this example, we find signs of relational leadership in that what was accomplished by the group of board members and allies was more than any of them could accomplish on their own.

The act of remembering together was equally synergistic. One could remember parts, another could build on this, and then they were able to remember events from 20

years ago that they had not discussed since. This sense of how relational leadership functions within different contexts resonates with other research of leadership in ID as a complex, context dependent role (Goodley, 1997, 2000, 2005; Roets, 2009). The focus groups demonstrated an excellent potential to demonstrate how "the practices of qualitative research finally move, without hesitation or encumbrance from the personal to the political" (Denzin & Lincoln, 1998, p. 261).

It is impossible to know what LMCBSS would have looked like if it had continued, or in what ways it might have changed the face of self-advocacy in British Columbia. The organizational environment, in which people with disabilities were involved in every aspect of operations, fostered the growth of strategic new initiatives and models of support and leadership. The perhaps unintended consequences of forming a self-advocate driven service provision organization was that it created a foundational platform for people with intellectual disabilities to speak to their agenda of equality, empowerment and education within the powerful provincial framework of service providers, advocacy agencies and governmental stakeholders. LMCBSS in many ways challenges the changing contemporary roles of charitable status service providing agencies. The "clientele" were also the agency leaders, and as an influential volunteer base was able to effectively advocate by using their power as an organization to support more rights-based reforms.

Summary and Implications for Practice

The fascination of this research was in how self-advocates created, led and ran their organization, based on the ideology of their movement, when they had no previous experience in service provision, and how did LMCBSS disappear, and how was it nearly lost as a story? The discussion was purposefully open-ended and emergent, as participants wanted to decide together on how their conversation would proceed. Given the history of tokenization and marginalization of people with ID in research frameworks (Kitchin, 2000), the sacrifice of a pre-set agenda of questions seemed less significant.

The story of LMCBSS demonstrates that people with intellectual disabilities can be effective leaders of projects, organizations, and research and, importantly, draws attention to the tension between those who would be self-determining and the agencies and organizations that support them. LMCBSS utilized a cross-platform approach, combining life, advocacy, skills building, residential, day and employment supports within a non-profit business model that focused on collaborative approaches and experiential learning among equal partners This created opportunities to represent people with disabilities to government, as well as access funds to address self-advocate goals. During its life, it allowed self-advocates to create an infrastructure of rights-based educational materials in the form of plain language documents and videos. This emancipatory framework differentiated them from the medical models of other organizations, based at the time on professionalization, traditional separation of services and assumptions of segregation.

Although it is possible, as the messaging of the large organizations that LMCBSS became part of states, that the “reach and impact of these smaller agencies . . . would be greater” (posAbilities, 2015, p. 16) after amalgamation, LMCBSS was singular. Even so many years later former board members spoke of agencies driven by parents' values, which they felt were different than their own, which would indicate that while there was some overlap, “the shared philosophy and values” (posAbilities, 2015, p. 1) of the small agencies were not the same.

The message of community inclusion is the valuation of diversity, yet the value of protecting and supporting diverse agencies that focused on different ways to serve people was not present. In fact, there was some sense that other agencies wanted to take their assets. An interesting thought is that at the time there was a more patriarchal government ministry in charge, which has been replaced by the more best practice, community involved Community Living British Columbia (CLBC). However, neither has CLBC been able to stand beside self-advocate leaders to protect one of the core ideas of its conceptualization in similar circumstances.

In the consolidation of LMCBSS with the other small agencies, there was also the final moment of decision-making when the self-advocate members of the society voted in agreement with the board's reluctant decision to back the motion. However, members spoke from the floor against it, reconsidered, called for another motion and voted, making a completely autonomous decision to stay intact. The response to this from the Executive Director seems to have been harsh, and rather than standing with them in their decision, he convinced them to vote a second time, in the way that was desired. Although theoretically they had hired him and he worked for them, in the end, the idea that they were the leaders of the agency was tested and discounted. This sequence of things has so many relational aspects: the idea that they needed to move forward together, and stop to listen to each other, and that even though they did not agree with what the Executive Director did, they were able to assume he made the best decision he was able to and forgive not only the decision but his methods.

An initial interest for self-advocates was in whether this would be a better time for something like the LMCBSS to exist. Analysis was conducted through a social constructionist lens (Gergen, 2009, 2015; McNamee, 2010) in hopes of finding ways that the historical data, both subjective and objective, might inform future possibilities for self-advocate governance projects. Aspects of this narrative that might inform similar projects in the future would be:

- Allies must recognize this prioritization of relational leadership (“leading in a circle”) in their dealings with self-advocate initiatives and “leadership might look different from what you expect.”
- Good decisions might take longer to talk through to make sure everyone is heard.
- There may be a need to support assertiveness training, and for allies to be sensitized to the way in which people with ID are raised in systems that assume and reward compliance.
- For those allies who become part of the self-advocate circle, there is a need to be aware of and honour the level of influence they have.

Regarding the role self-advocate leaders played, while there was good learning about their history and accomplishments, little was learned that would make the success of such a project more likely given that it was the apparent victim of external pressures. Any recreation of the organization would require that the systems it is embedded in change significantly.

The story of LMCBSS that emerged was a complex one, in which words and names shifted meanings, and people thought to have done wrong, both with and without disabilities, were shown as actors in a more holistic relational narrative. Importantly, they came to understand in these conversations that other small agencies had also made the same choice to amalgamate, while others made different choices, which they had not known. Their allies had created singular opportunities, and in the end tried to act proactively and protectively. Those classified as vulnerable in deficit-based assessments were, in fact, the organizing forces who held on to stories, memories, contracts and documents and in the end made the call for a debriefing that would inform others.

The question of whether or not LMCBSS was the victim of hegemonic assumptions, if not intentions, turned out to be simplistic and combative, and unanswerable. An important aspect of the research, then, was the discovery that no one did anything "wrong" but that the agency was subjected to governmental pressures and people who cared deeply made what they felt was the best choice at the time. Other people who cared equally deeply about other organizations made similar or other choices. The self-advocate board members had not realized this. It is probable that the more recent decision to not include self-advocate board members in the governance of CLBC was within a similar pattern. The learning in this is that the need for debriefing may be more acute given a population which may assume they are at fault, having been convinced of their deficits at so many points in their lives.

Goodley (1997) points out that in an increasing body of research, often conducted in collaboration with people with disabilities, self-advocacy is not simply one thing, but "a diverse assemblage" (p. 367) of "multi-faceted" (p. 368) groups and leaders

serving different agendas. According to Crawley (as cited in Goodley, 1997), “We *cannot* assume that the increase in the frequency of so-called self-advocacy groups directly relates to an increase in tangible and meaningful opportunities for self-advocacy and self-determination” (p. 368). Similarly, Aspis (1997) points out that self-advocate training that does not incorporate education on challenging policies and law has limited scope. Without this more fully informed focus, the movement is subverted to “become a tool to find out what people with learning difficulties think of services rather than to challenge the philosophy of services and system that creates them and their inherent limitations” (Aspis, 1997, p. 592). For example, in British Columbia a great deal of funding and energy is put into the province's largest self-advocate involved project, includeME, which collects data through self-advocate interviews of their peers and has involved “over 70 service providers to survey more than 3,000 individuals about how they feel about their independence, social participation and well-being” (CLBC, n.d., para. 2). Both CLBC and agencies richly fund this project, in comparison to the potential more open ended and uncontrolled self-advocate activities (and, potentially, evaluations). From CLBC’s (2017) $953.8 million budget, the largest provincial self-advocacy organization, B.C. People First, continues to do their work with the same federal grant for $10,000, which has not increased for nearly two decades.

These financial issues are reminiscent of Malacrida’s (2015) statement that it is difficult even for trained historians “to construct a balanced history of the treatment of individuals with mental differences [as] . . . such individuals are typically either erased from the record, or their stories are told through the voices of helpers, authorities, professionals, and those who saw them more as categories than as people of value or interest in their own rights” (p. 5) and that often the act of characterizing someone as mentally competent or not has to do with “with broader social and economic shifts” (p. 5). The example of LMCBSS not least shows us what self-advocates can do with some discretionary funding and also their sophistication in thinking to seek more diverse sources that came without strings attached.

History is not a static thing that we come to know, once and for all, but always contextual and mutually constructed, given access and voice. Complexity theorist Alfonso Montuori (1995) writes that it is not

> *something we browse through occasionally for purposes of erudition and arcane knowledge of bygone eras: history is in our flesh and bones – and in our minds. Darwin's great revolution was to show us that we are our history. The great 90s revolution of complexity and chaos shows us that history is not determined, that it is the contingent co-creation of individuals and their environments.* (p. 19)

This new knowledge and reframing of the history of LMCBSS appeared to bring a sense of resolution and shared understanding to participants that this story really was more complex than it might have seemed. Their significance as the first service providing organization created by people with intellectual disabilities to support their peers would have disappeared without the active intervention of people with ID. Thirty years later, service providing organizations which require even 51% of their leaders to be people with disabilities, such as the Iowa Independent Living Council, are "unique" (Iowa Statewide Independent Living Council, n.d., para. 1).

LMCBSS as an example demonstrates that people with intellectual disabilities can be effective leaders and have a leadership culture which is relational and holistic. Within this it was possible for them to manage and lead the organization's operations, strategic aspects, projects, and research. Their experience also underlines that when given opportunities for leadership, people with disabilities, often under the weight of years of negative feedback and assumed deficits, actively require debriefing processes and in their absence may assume they have failed. There is a clear potential relationship between supporting self-advocacy in all its variations and supporting community-based research that is meaningful to the participants.

Limitations and Potential for Future Research

These stories of LMCBSS represent some but not all of the people and perspectives involved in the organization. Some former staff, allies, and stakeholders were approached to participate but were unavailable or unwilling, and in the end self-advocate leaders felt that they wanted to just tell their story. Additional research might

follow up with these stakeholders and also with those former board members who were unable to attend. This narrative reflects the focus group's discussion of one local agency created with allies within a system that was open to the potential of such an organization, at least for a while.

Malacrida (2015) draws on a number of authors in her argument that for people with ID such “narratives open the possibility of claiming one's memories as legitimate and telling one's experiences as a counter-narrative to the dominant medical model” (p. 242). There seems great potential in looking at how organizational models that support people with disabilities are derived from this medical/institutional/school-based model, and examining how this continues to subjugate people with positing their support.

Without listening to, understanding and acting on these stories, the persons affected by such systems are conceived of as a combination of diseases, gaps, lacks, deficits and conditions and their subjective understanding of events and contexts “is regarded as irrelevant” (Malacrida, 2015, p. 242), whereas the narrative that arises from them has the power “to reclaim knowledge by making memories public [and] thus offers individuals an opportunity to bear witness to their experience, to affirm personal perspectives” (p. 242) as a way of challenging dominant ideologies and authenticating how people have been affected by “the workings of power and domination within the medical encounter” (p. 242). She notes that other authors have suggested that narrative and memory work is useful to a “broad range of people who have been harmed or marginalized by powerful institutions” (Malacrida, 2015, p. 242) to ensure that those in power, through “innocence or ignorance” (p. 241) will not repeat the mistakes of the past. As Pat Worth's comment, well known in self-advocate circles, that institutions are a way of thinking and not a place, suggests, there are organizational and cultural interactions and patterns that continue to disempower and subvert the emancipation of people with ID.

The implications for service providers and government are clear in that if people are to be empowered, the projects they direct must also be respected and protected.

Allies must be equally invested. Other agencies started at the same time continue to offer some alternatives to what are sometimes termed “big box” services, which offer few choices and have continued to be the preferred organizational model for government funders because of assumptions about efficiency. While conversations about “innovative” alternatives continue, the bulk of funding continues to support segregated programs and housing.

Now that this iteration of the story has been told, it will be interesting to seize opportunities to share it further and see what emerges, out of history, and as possibilities for the future. Other forgotten parts of their history have already emerged, such as the Eve case (see Appendix B) and a self-advocate run business that had a similar fate to that of LMCBSS Not least this research project challenges the nature of local history by using social constructionist ideology and research methods to include those with little literacy. This offers them an alternative to being represented by others. A possible next step for the participants could be the formation of a local inclusive research group that helped others formulate questions and developed increasing skills and experience in supporting peers to debrief through a balanced process of balanced self and collective reflection.

Conclusion

There was a sense of satisfaction in participants from telling their story together, seeing the graphic recording that arose out of it, and knowing that it would be shared with others, and they might build on these ideas. They felt good about documenting this nearly lost part of their history. The documents, with a copy of both this research paper and the plain language version, were reproduced as packages for each of the participants, and digital packages were sent to local archivists, the Canadian Museum of Human Rights and People First of Canada. A plain language and graphics version of the paper is in the process of being created for distribution through social media to the province’s self-advocates through B.C. People First and selfadvocatenet.com, a web-based resource run by self-advocates for their peers. It can be accessed at www.imagineacircle.com under “research.” The graphic document was also distributed

as a handout for an Internet-based presentation by self-advocate partners and the researcher.

References

Aspis, S. (1997). Self-advocacy for people with learning difficulties: Does it have a future? *Disability & Society, 12*(4), 647–654. doi:10.1080/09687599727182

Barnes, C. (2002). 'Emancipatory disability research': Project or process? *Journal of Research in Special Educational Needs, 2*(1), 233–244. doi:10.1111/j.1471-3802.2002.00157.x

Bates, P., & Davis, F. A. (2004). Social capital, social inclusion and services for people with learning disabilities. *Disability & Society, 19*(3), 195–207. doi:10.1080/0968759042000204202.

Beresford, P. (2003). *It's our lives: A short theory of knowledge, distance and experience*. Victoria, Canada: Open Services Project.

Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 27*(1), 3–12. doi:10.1111/jar.12083

Block, P. (2008). *Community: The structure of belonging*. San Francisco, CA: Berrett-Koehler.

Caldwell, K. (2013, June 14). Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research, 14*(4), 488–507. doi:10.1177/1468794113490718

Caldwell, K., & Nellis, T. (2014). *The future of dyadic interviewing*. Retrieved from http://conference.tash.org/sessions/the-future-of-dyadic-interviewing/

Canada Revenue Agency. (2017, January). *Charities listings – advanced search.* Retrieved from http://www.cra-arc.gc.ca/ebci/haip/srch/advancedsearch-eng.action

Community Living British Columbia. (n.d.). *Ten years later: Evaluating progress through the Include Me! quality of life survey.* Retrieved from http://www.communitylivingbc.ca/news-2/a-special-10-year-anniversary-update/the-include-me-quality-of-life-survey/

Community Living British Columbia. (2017, February 24). *Province announces budget.* Retrieved from http://www.communitylivingbc.ca/2017/02/province-announces-budget/

Craig, D., & Bigby, C. (2015). “She's been involved in everything as far as I can see”: Supporting the active participation of people with intellectual disability in community groups. *Journal of Intellectual and Developmental Disability, 40*(1), 12–25. doi:10.3109/13668250.2014.977235

Crawford, C. (2004). *Gathering momentum: Mobilizing to transform community living in BC.* Toronto, Canada: L'Institut Roeher Institute.

Denzin, N. K., & Lincoln, Y. S. (Eds.). (1998). *Collecting and interpreting qualitative materials*. London, United Kingdom: Sage.

Drake, R. F. (1992). Consumer participation: The voluntary sector and the concept of power. *Disability, Handicap and Society, 7*(3), 267–278. doi:10.1080/02674649266780271

Drake, R. F. (1994). The exclusion of disabled people from positions of power in British voluntary organisations. *Disability & Society, 9*(4), 461–480. doi:10.1080/09687599466780461

Drake, R. F. (1996). Charities, authority and disabled people: A qualitative study. *Disability and Society, 11*(1), 5–23. http://dx.doi.org/10.1080/09687599650023290

Fowlie, J. (2011, November 18). Community Living B.C. board reconfirms organization lost its way. *Vancouver Sun*.

Fratangelo, P. (n.d.). *How rules push away friends by*. Retrieved from http://oclinc.org/links/rules.htm

Frawley, P., & Bigby, C. (2011). Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia. *Journal of Intellectual & Developmental Disability, 36*(1), 27–38. doi:10.3109/13668250.2010.549465

Friedman, M., & Beckwith, R.-M. (2013, October). *National study, beyond tokenism: Executive summary*. Retrieved from http://www.beyondtokenism.com/wp-content/uploads/2016/05/BeyondTokenismExecutiveSummary-final.pdf

Gergen, K. J. (2009). *Relational being: Beyond self and community* [Electronic version]. Retrieved from https://www.amazon.ca/Relational-Being-Beyond-Self-Community/dp/019984626X

Gergen, K. J. (2015). From mirroring to world-making: Research as future forming. *Journal for the Theory of Social Behaviour, 45*(3), 287–310. doi:10.1111/jtsb.12075

Goodley, D. (1997). Locating self-advocacy in models of disability: Understanding disability in the support of self-advocates with learning difficulties. *Disability & Society, 12*(3), 367–379. doi:10.1080/09687599727227

Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties: The politics of resilience.* Berkshire, United Kingdom: Open University Press.

Goodley, D. (2005). Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities, 9*(4), 333–343. doi:10.1177/1744629505059267

Hagel, J. (2013, October 21). Narrative and passion [Web log post]. Retrieved from http://edgeperspectives.typepad.com/edge_perspectives/2013/10/narrative-and-passion.html

Handcock, M. S., & Gile, K. J. (2011). Comment: On the concept of snowball sampling. *Sociological Methodology, 41*(1), 367–371. doi:10.1111/j.1467-9531.2011.01243.x

Iowa Statewide Independent Living Council. (n.d.). *What are centers for independent living?* Retrieved from http://www.iowasilc.org/cilinfo.html

Johannes, A. (2013). *People with intellectual disabilities as leaders: Collaboratively identifying strategies for success, using graphic facilitation* (Master's thesis). Athabasca University, Canada.

Johannes, A. (2016). Sensemaking through arts infused person centred planning processes. In B. Agerbeck, K. Bird, S. Bradd, & J. Shepherd (Eds.), *Sensemaking: Presence, emergence and connection through visual practice*. Seattle, WA: Amazon.

Johannes, A. (2017). *A meta-circle of Leaders with intellectual disabilities discuss what's helpful in the leadership of their lives, the groups they are part of and in their communities*. Unpublished manuscript.

Johnson, K. W., Walmsley J., & Wolfe, M. (2010). *People with intellectual disabilities: Towards a good life?* Bristol, United Kingdom: Policy Press.

Kitchin, R. (2000). The researched opinions on research: Disabled people and disability research. *Disability & Society, 15*(1), 25–47. doi:10.1080/09687590025757

Lorde, A. (1979). The *master's tools will never dismantle the master's house*. Retrieved from http://www.historyisaweapon.com/defcon1/lordedismantle.html

Lower Mainland Community-Based Services Society. (1993). *Forms and appendices: Appendix B: LMCBSS polices and procedures*. Burnaby, Canada: Author.

Lower Mainland Community-Based Services Society. (1988, July 21). *Certificate of incorporation*. Victoria, Canada: Government of British Columbia.

Lower Mainland Community-Based Services Society. (1989). *Policy and procedures manual*. Burnaby, Canada: Author.

Lower Mainland Community-Based Services Society. (1996). *Ridgeview heights: Program update.* Burnaby, Canada: Author.

Malacrida, C. (2015). *A special hell: Institutional life in Alberta's eugenic years* [Electronic version]. Retrieved from https://www.amazon.ca/Special-Hell-Institutional-Albertas-Eugenic-ebook/dp/B00T9Z29II/ref=sr_1_1?ie=UTF8&qid=1500913105&sr=8-1&keywords=kindle+A+special+hell%3A+Institutional+life+in+Alberta%27s+eugenic+years

McNamee, S. (2010). Research as social construction: Transformative inquiry. *Saúde & Transformação/Social Health & Social Change, 1*(1), 9–19.

Mittler, P. (2008). Planning for the 2040s: Everybody's business. *British Journal of Special Education, 35*(1), 3–10. doi:10.1111/j.1467-8578.2008.00363.x

Montuori, A. (1995). Word. *Komotion International, 8*, 20–26.

Mullen, K. C. (2013). *I see what you mean: Visual and participatory climate change communication* (Master's thesis). Colorado State University, Colorado, Fort Collins.

Mullen, K. C., & Thompson, J. L. (2013). Graphic recording: Using vivid visuals to communicate climate change. *The Electronic Journal of Communication, 23*(3). Retrieved from http://www.cios.org/www.cios.org/EJCPUBLIC/023/3/023034.html

O'Brien, C. L., & O'Brien, J. (2000). *The origins of person-centered planning: A community of practice perspective.* Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.502.8388&rep=rep1&type=pdf

Pathways Abilities Society. (2015). *Policy: Resident care, social access and visitors.* Retrieved from http://www.pathwayskelowna.ca/wp-content/uploads/2014/04/Resident-Care-and-Social-Access-Policy.doc

Pitonyak, D. (n.d.). *Who holds your story?* Retrieved from http://www.dimagine.com/WhoHoldsYourStory.pdf

posAbilities. (2015). *posAbilities Histogram*. Burnaby, Canada: Author.

PosAbilities. (2016). *Our history*. Retrieved from http://posabilities.ca/about-us/our-history/

Rapley, M. (2004). *The social construction of intellectual disability*. Cambridge, United Kingdom: Cambridge University Press.

Reimer, S. (1996). *History of Lower Mainland Community-Based Services Society*. Burnaby, Canada: Author.

Roets, G. (2009). Unravelling Mr President's nomad lands: Travelling to interdisciplinary frontiers of knowledge in disability studies. *Disability & Society, 24*(6), 689–701. doi:10.1080/09687590903160142

Saidel, J. R. (1998). Expanding the governance construct: Functions and contributions of nonprofit advisory groups. *Nonprofit and Voluntary Sector Quarterly, 27*(4), 421–436. doi:10.1177/0899764098274003

Sega, S. P., Silverman, C., & Temkin, T. (1996). Measuring empowerment in client-run self-help agencies. *Community Mental Health Journal, 31*(3), 215–227. doi:10.1007/BF02188748

Snow, J. (1994). *What's really worth doing and how to do it*. Toronto, Canada: Inclusion Press.

Titchkosky, T. (2011). *The question of access: Disability, space, meaning.* Toronto, Canada: University of Toronto Press.

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society, 16*(2), 187–205. doi:10.1080 /09687590120035807

Wehmeyer, M. L. (1999). A functional model of self-determination: Describing development and implementing instruction. *Focus Autism Other Developmental Disabilities, 14*(1), 53–61. doi:10.1177/108835769901400107

Wehmeyer, M. L., & Abery, B. H. (2013). Self-determination and choice. *Intellectual and Developmental Disabilities, 51*(5), 399–411. doi:10.1352/1934-9556-51.5.399.

Wehmeyer, M., & Laurence, M. (1995). Whose future is it anyway? Promoting student involvement in transition planning. *Career Development for Exceptional Individuals, 18*(2), 69–83. doi:10.1177/088572889501800202

Wehmeyer, M., H. Bersani, J., & Gagne, R. (2000). Riding the third wave: Self-determination and self-advocacy in the 21st century. In M. L. Wehmeyer, & J. Paton (Eds.), *Mental retardation in the 21st century* (pp. 106–151). Austin, TX: Pro-Ed.

Worrell, B. (1988). *Advice for advisors: People first*. Downsview, Canada: G Allan Roeher Inst Kinsman.

"Leadership is a complex social process enacted by the many. It is not a rational, scientific endeavour practised by a few, gifted individuals. That is to say, it is an emergent phenomenon that is co-created in the moment of people's everyday interactions. As such, it is a normal characteristic of the day-to-day relationships of interdependent people." — Chris Rodgers (2012)

Chapter 5:

A Meta-Circle of Leaders with Intellectual Disabilities Discuss What is Helpful in the Leadership of their Lives, the Groups they are Part of and in their Communities

Abstract

This research sought the input of people with intellectual disabilities through a series of "community conversations" which were co-created (planned for), co-organized and co-facilitated with them. In different localities, people came together to share stories of successful and satisfying leadership experiences in their lives which graphically recorded at the front of the room. This process gave them opportunities for member checking and allowed for quickly building a complex conversation together, as they could see their discussion. Results of these dialogues were collected and analyzed by grouping them thematically, and then presented to a meta-circle of experienced self-advocate leaders for feedback. These leaders expanded on and deepened the ideas that arose in the "community conversations" by reflecting on their experiences of leadership. Their reflections led to the creation of two documents on how to support leadership locally, one for self-advocates and one for allies and organizations. Ideas for further research are listed at the end.

Relationship of this Article to the dissertation

This dissertation's research addressed the problem of the lack of knowledge about how people with ID are leaders and whether they consistently have leadership opportunities and are involved in ways that are not tokenistic. This portion of the research allowed us to focus on the primary research question: for people with ID, what works to support them in leadership in their lives, groups and communities? It also allowed for the further examination and clarification of how people with ID may lead differently than we expect.

As with the other parts of this research that involved persons with ID graphic recording allowed a holistic sense of the conversation.

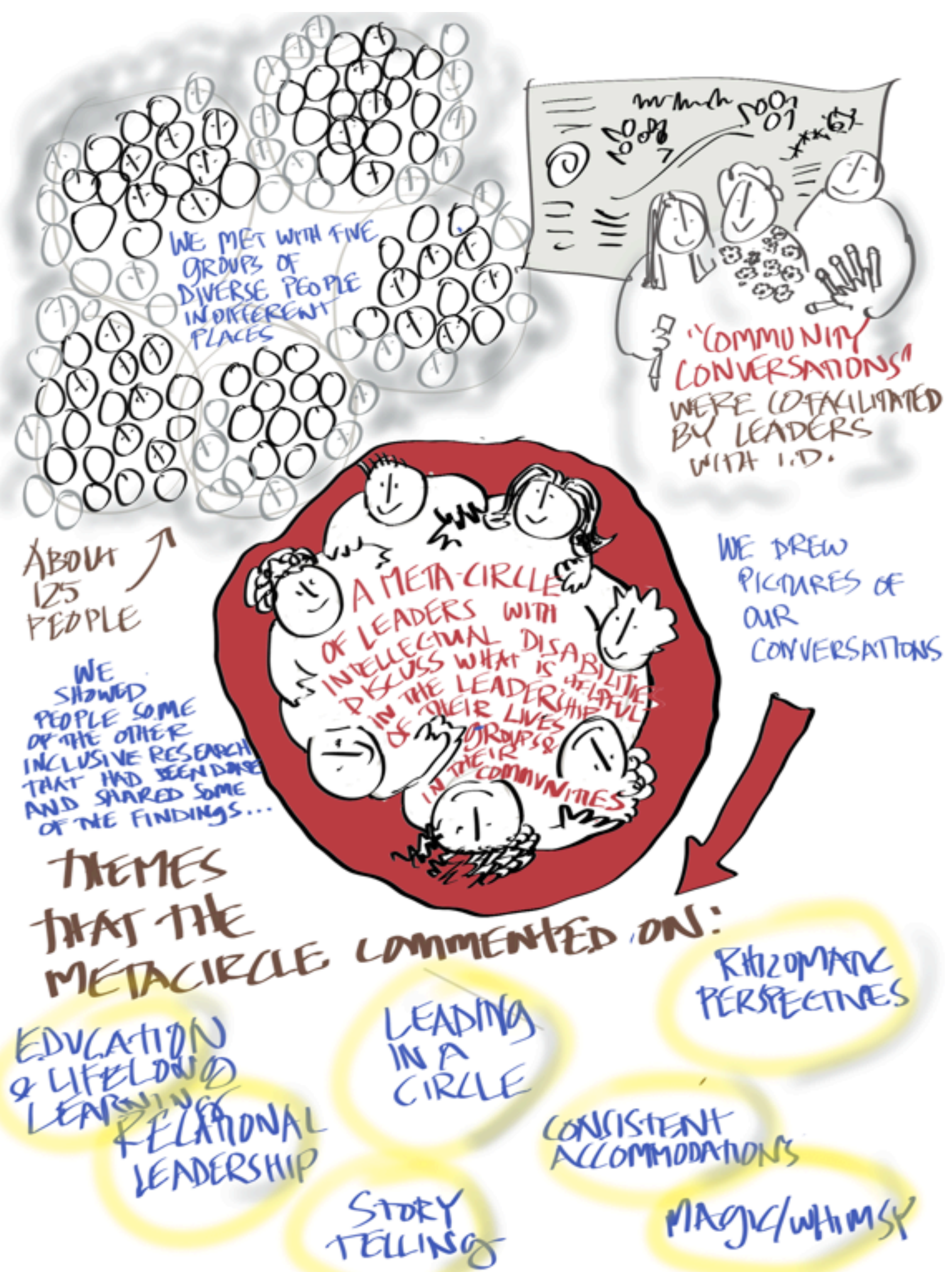


Figure 26. Graphic rendering of this paper for discussion with people with disabilities.

Introduction

This research examines two social problems for people with ID: First, that they are often not fully included in decision-making in their lives, groups, or communities. Second, when included, their contributions are perceived to be individual and the exception rather than collective and emancipatory. Learning about what has best worked to include them as authentic leaders potentially increases their opportunities to be included and leverages their ideas and impact.

Leadership as an identified quality has become increasingly important throughout democratized Western civilization but is assumed to be a meritocratic quality in limited quantities. How people with intellectual disabilities fit within this paradigm has been challenging to understand (Carter, Swedeen, Walter, Moss, & Hsin, 2011, p. 58) and research has often been about potential (e.g., Chenoweth & Clements, 2011) rather than the documentation of self-advocate experiences.

The interest of this research was in a non-assumptive approach, designed collaboratively with people who had been labeled as having ID. They had four objectives. First, they wanted to identify from a strengths-based self-advocacy perspective what leadership is, from the widest possible range of peers. Second, they wanted to know what previous research and current thinking existed. Third, they wanted clear information about how they and their allies could support the leadership of self-advocates in their lives, groups, and communities. Fourth, self-advocates wanted the research to be useful and accessible and to this end envisioned iterative and diverse opportunities for dissemination of the growing body of knowledge.

Increasingly, people with ID participate in groups as leaders. There is agreement that in a “civil democracy” the role of government and civic leaders “is to help dismantle barriers so that people can more fully participate in their communities, both for the betterment of their society and for the fulfillment of their personal potential” (Vancouver Sun Editorial Board, 2016, para. 1). Internationally, the United Nations (2006) *Convention on the Rights of Persons with Disabilities* sets new standards and posits “their participation in the civil, political, economic, social and cultural spheres

with equal opportunities, in both developing and developed countries" (p. 3) as a way "make a significant contribution to redressing the profound social disadvantage of persons with disabilities" (p. 3). This vision is expanded by their statement that "full participation" will result in "significant advances in the human, social and economic development of society" (United Nations, n.d., p. 2), occur through supporting active involvement of people with ID in "decision-making processes about policies and programmes, including those directly concerning them" (p. 2).

Nationally, Canada's newly appointed Minister of Persons with Disabilities stated in her introductory speech, "An accessible Canada is more than how we build our spaces; it is about what and how we think" (Qualtrough, 2016, para. 17) and encouraging citizens to be constantly considering the full participation of people with disabilities as "an integral part of everything we do" (para. 19). She encourages a new proactive approach that does not involve the judicial system responding to violations of rights, which "unfairly burdens Canadians to ever defend our rights" (Qualtrough, 2016, para. 21) as such "vigilance is exhausting and expensive. Further, I think it's fundamentally wrong" (para. 22). Instead, she writes, citizens should think critically about inclusion until "this way of thinking becomes a habit [and] we shift culture" (Qualtrough, 2016, para. 25).

This concern to include people with ID in all parts of culture including decision-making is global. For example, it is part of the new inclusive oversight of the Learning Disability Partnership Boards in the United Kingdom, (Riddington, 2012), various Australian initiatives (Chenoweth & Clements, 2011) and in British Columbia, where this research takes place, the creation of a new crown corporation required in its constitution the inclusion of self-advocates on the governance board. However, such well-intended initiatives have been somewhat problematic (e.g., Fyson & Fox, 2014; Fyson & Simmons, 2003), exemplified by the British Columbia's government's unilateral, undiscussed, and still unexplained decision to simply remove the self-advocate representation clause from the C.L.B.C. constitution (Stainton, 2009).

Contemporarily, almost every agency and organization that provides services to people with disabilities includes self-advocate advisors or board members. The recent "Beyond Tokenism" study, the largest of its kind in North America, found some 756 people with intellectual disabilities serving on boards in the United States (Friedman & Beckwith, 2013). However, that the study, requested by self-advocates, was felt necessary is indicative of these complex issues.

The complexity of leadership regarding the lives of people with intellectual disabilities is interwoven, as in so many other parts of their lives, with issues of agency, independence, and interdependence (Ashby, Jung, Woodfield, Vroman, & Orsati, 2015). Culturally, our growing interest in diversity and in the ways that other cultures lead creates new openings for understanding differences and rethinking assumptions. For example, leadership in the Lakota culture differed so much from the Euro-American concept of permanent, democratic or hereditary leadership that it led to significant misunderstandings as colonizing European leaders sought agreements with those they assumed were their counterparts (North Dakota Studies, n.d.). Their refusal to agree on permanent, identified leaders and lack of understanding that some might make decisions for others, which not all might agree with, supported the promoted belief that they were uncivilized. This fuelled further generational disempowerment through moral aspersions such as the idea of an "Indian giver" (someone who cannot keep their word).

With leaders with ID, similar unaddressed assumptions, such as their perceived lack of capacity for abstract thought, intrude on what Wolfensberger identified as the concept of "polity" – how we get along together (Wolfensberger, 1994). That people with ID are not considered to have the capacity to be involved in the governance of various parts of our communities is belied, often unacknowledged by their more than 40-year leadership history, in Canada as People First, sponsoring and supporting self-advocate driven projects, and engaging with government at all levels (People First of Canada, n.d.).

Leadership, as it is identified by self-advocate leaders who collaborated in this research, provides a lens to allow the identification of a continuum of empowerment

practices in self-determination, leadership roles within groups of others with disabilities, and within community groups that can lead to further equity and also to the enrichment of our communities.

Theoretical Underpinnings

Social constructionism is a significant theory to bring to critical disability studies as it addresses people with intellectual disabilities, a population that has historically been shut away and excluded. Contemporarily, some of these same people are now integral, successful leaders. It is difficult to fathom why people with the same etiology and background live lives with absolutely different outcomes, literally within feet of each other, given different supports.

There has been relatively little research about leadership in the lives of people with ID and surprisingly little about their presence and progress in newly mandated positions of shared leadership in organizations and governmental bodies (e.g., Friedman & Beckwith, 2013; Fyson & Fox, 2014; Fyson & Simone, 2003). In this research, the body of collaborators wanted to move away from a research methodology that imagined fixed points and final answers, making pronouncements and taking positions which had not been useful to them, and into processes in which "knowledge making should not be cumulative, but continuous" (Gergen, 2015b, pp. 52–53). Thus, social constructionist methods fit well into their concepts:

> *Elsewhere I have characterized constructionism as a reflective pragmatism (Gergen, 2014). That is, knowledge should not be equated with Truth, but with utility. However, utility must be judged in terms of values – useful to whom, and for what purposes. What values are being served by an inquiry, and whose values are they?* (Gergen, 2015b, pp. 52–53)

A social constructionist approach to inclusive research with people with ID has made it possible to be reasonably certain that these results are useful to those who participated.

Methodology

Inclusive/collaborative research.

This research project was supported by a self-advocate advisory group that met ad hoc in person and online to advise and collaborate. They were active co-creators of the research questions, the research model and the methodology to iteratively report back on the findings. They strongly believed, with the researcher, that "the greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted" (Beresford, 2003, p. 4). Canadian critical disabilities studies have not yet particularly focused on inclusive research in the same way that British (Walmsley & Johnson, 2003), Australian (Bigby, Frawley, & Ramcharan, 2014), and European (Roets, 2009) research has. However, people with ID in British Columbia have been involved with and are knowledgeable about various kinds of collaborative research projects (e.g., Garrucho, Barry, Malatest, & Chou, 2013; Feduck, 2012), and were interested in learning more about how research might work. As with other people with ID in other countries (Kitchin, 2000), they were frustrated with a long history of being involved in research in which the results were not used to their benefit or shared with them in ways they could understand.

Our framework was collaborative in that "people with and without disabilities who work together have both shared and distinct purposes which are given similar attention and make contributions that are equally valued" (Bigby et al., 2014, p. 8). For example, when we broke down their frustration about how research did not serve them and their difficulty in understanding it, they argued for these considerations:

- Co-created research questions that were meaningful to them;
- an accessible shared body of the pre-existing literature and research;
- graphically recorded workshops so participants could see their contributions and build on their discussion (Johannes, 2013);
- an iterative feedback loop to share the accruing results in diverse ways; and
- tools that would be locally useful to local participants to support their leadership aspirations and initiate change in their lives and communities.

Finally, they saw "reporting back" as involving the whole provincial community of self-advocates, as well as a more academic audience.

These insights were a good example of how the research project advisors and participants thought critically about their roles and the results they hoped for while the researcher brought to the project an understanding of academic procedures and research processes. Both parties were excited about the potential of a research model that was intentionally iterative, inclusive, useful to local change agents, "future forming" (Gergen, 2015a, p. 287) and open-ended. All workshops were co-facilitated by self-advocates (Caldwell, 2013; Caldwell & Nellis, n.d.), with them assuming increasing mastery and leadership in the sessions, and graphically recorded with a person with a disability. The researcher described the research project plan and developed tools, which were the subject of a successful academic ethics review.

Research Questions

Research suggests that self-advocate participation in the design and facilitation of research projects makes the events and the collected data more meaningful to their lives (Caldwell, 2013; Kitchin, 2000; Walmsley & Johnson, 2003). The initial research questions about how allies might better support self-advocate leaders were critiqued, challenged, and re-shaped. It was considered assumptive that people might need allies without disabilities, and perhaps targeted a certain kind of self-advocate leader supported in one kind of leadership dynamic. Further, although they agreed it might be important as one of many considerations, it was not a question of significance to them. They broadened and clarified the definition of leadership to include "leadership in your life" because they said self-determination was a primary form of leadership and to not see this might be an act of privilege. A person spending most of their energy negotiating their rights and choices within environments that were, if well-meaning, repressive, was equally a leader. This idea speaks to a tension previously identified by Buchanan and Walmsley (2006):

> *It is possible to discern a number of different, sometimes competing, constructions of self-advocacy. As Chapman (2005) has pointed out, there is an*

> *inherent tension between individuals using self-advocacy groups as a mechanism to gain confidence and skills in speaking up, and self-advocacy organizations campaigning for change on behalf of the collective. Self-advocacy as a means of individuals gaining confidence requires a continual process of inducting and supporting new members, whereas if they are to be effective campaigning organizations, self-advocacy groups need people with experience and sophisticated skills in debate and management of budgets and people. These do not sit easily together.* (p. 134)

The advisory group wanted the research focus to be on what "felt successful and satisfying," rather than "success," and were certain the way to do this was through stories, rather than other research instruments such as surveys.

Self-advocates co-created five plain language bullet point primary questions with the researcher:

> *"Leadership means to take action. What are some stories about what has been satisfying or successful for you as a leader in:*
>
> *A. Your life*
> *B. Groups you belong to*
> *C. Your community?"*

Five informal community conversations on the topic of "what works" to support the leadership of people with intellectual disabilities took place at conferences and workshops over 2 years, in British Columbia, Canada and Portland, Oregon. Attendees were invited with variations of this introduction:

> *What Works: Self-Advocate Leadership in Life, Groups and Community*
>
> *While there is a solid history of self-advocate leadership in North America, little research has been done on what supports work well. This session combines findings from a focus group, informal discussions and secondary research to examine the issues appreciatively in hopes of better practices. Knowing that we must ethically involve those we support in decision making at every level, an idea now reinforced by the ratification of the United Nations Convention on the Rights of Persons with Disabilities, we also have good evidence that it is good for everyone in participatory decision making to be inclusive. We are on the verge of being able to bring these leaders into community, an ultimate act of progressive leadership, which is the theme of this conference.* (TASH, 2015, para. 6–10)

Community Conversations about "What Works to Support Self Advocate Leadership in their Lives, Groups and Communities" were held in the following places:

1. Inclusion B.C., Keep Moving Don't Stop, Sheraton Wall Centre, Vancouver, BC, May 28–30, 2015;
2. Parksville and District Association for Community Living, "Building Personal Support Networks with Self Advocate Leaders," Oct 8, 2015, Parksville, BC.
3. UBC Centre for Inclusion and Citizenship, Claiming Full Citizenship: Self Determination, Personalization and Individualized Funding: 2015 International Conference, Hyatt Regency, Vancouver, BC, October 15–17, 2015;
4. TASH, Celebrating 40 Years of Progressive Leadership, Portland, OR, December 2–4, 2015;
5. Inclusion BC, "Ignite" Conference, Prince George, BC, June 22–25, 2015.

Approximately 125 people attended these five conversations, comprised of about 75% self-advocates, 10% family members, 10% allies (volunteers to self-advocate groups and community friends) and 5% policymakers. Sessions began with a discussion of inclusive research and research processes, an accessible literature review of current research on self-advocate leadership and some discussion of how these ideas related to our growing body of information. Participants discussed three questions by self-advocate co-facilitators:

1. What is a good story of a self-advocate leader that you would like to share?
2. What has helped you as a leader?
3. What would you like people in your community and the organizations that you are part of to know to support you better as a leader?

Sessions ended with a "planning for leadership" worksheet on which participants were supported by peers, allies, and facilitators to document their ideas about increasing leadership capacity and potential to take home to their communities.

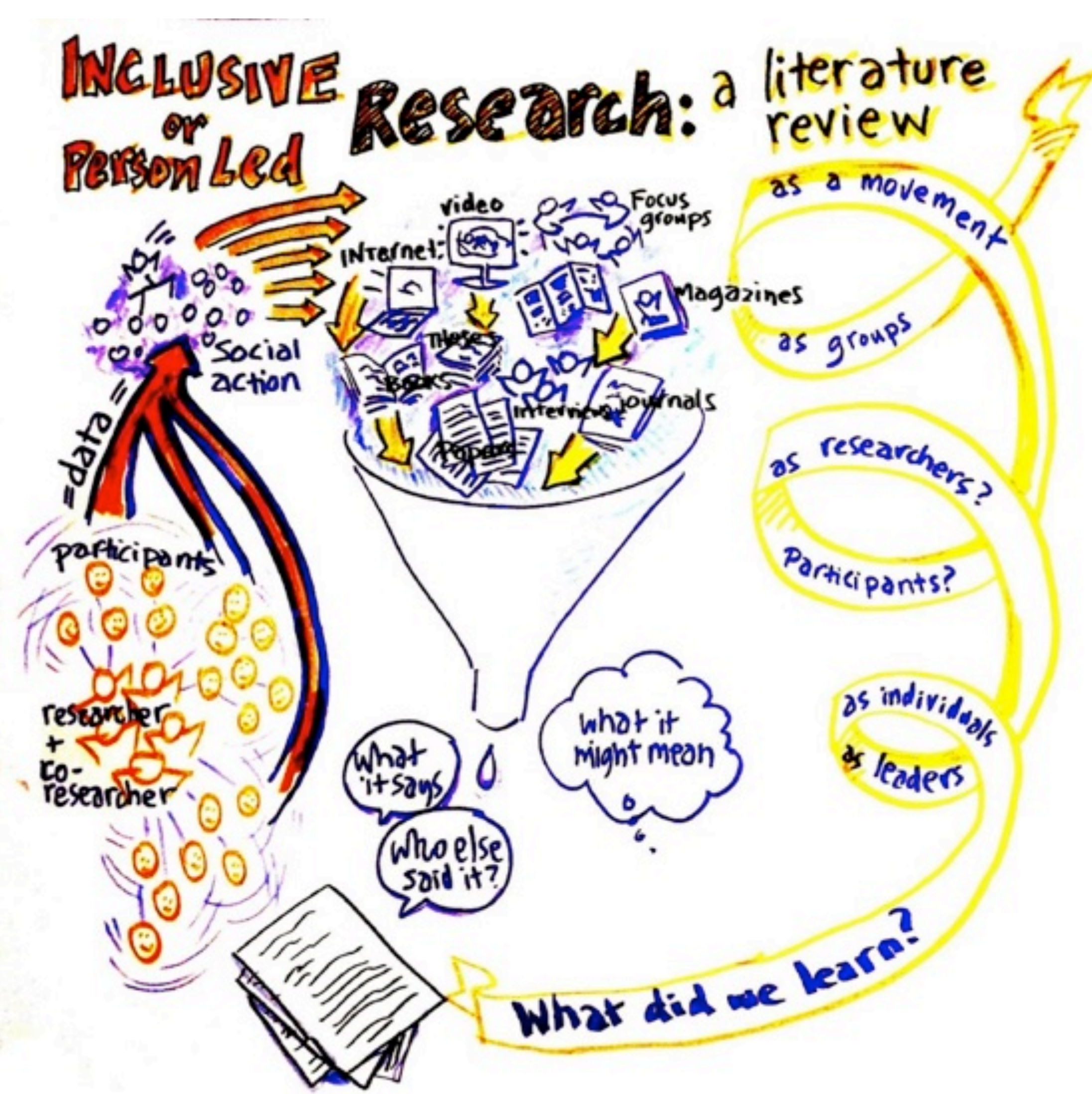


Figure 27. This and similar graphics were used to explain research processes to participants.

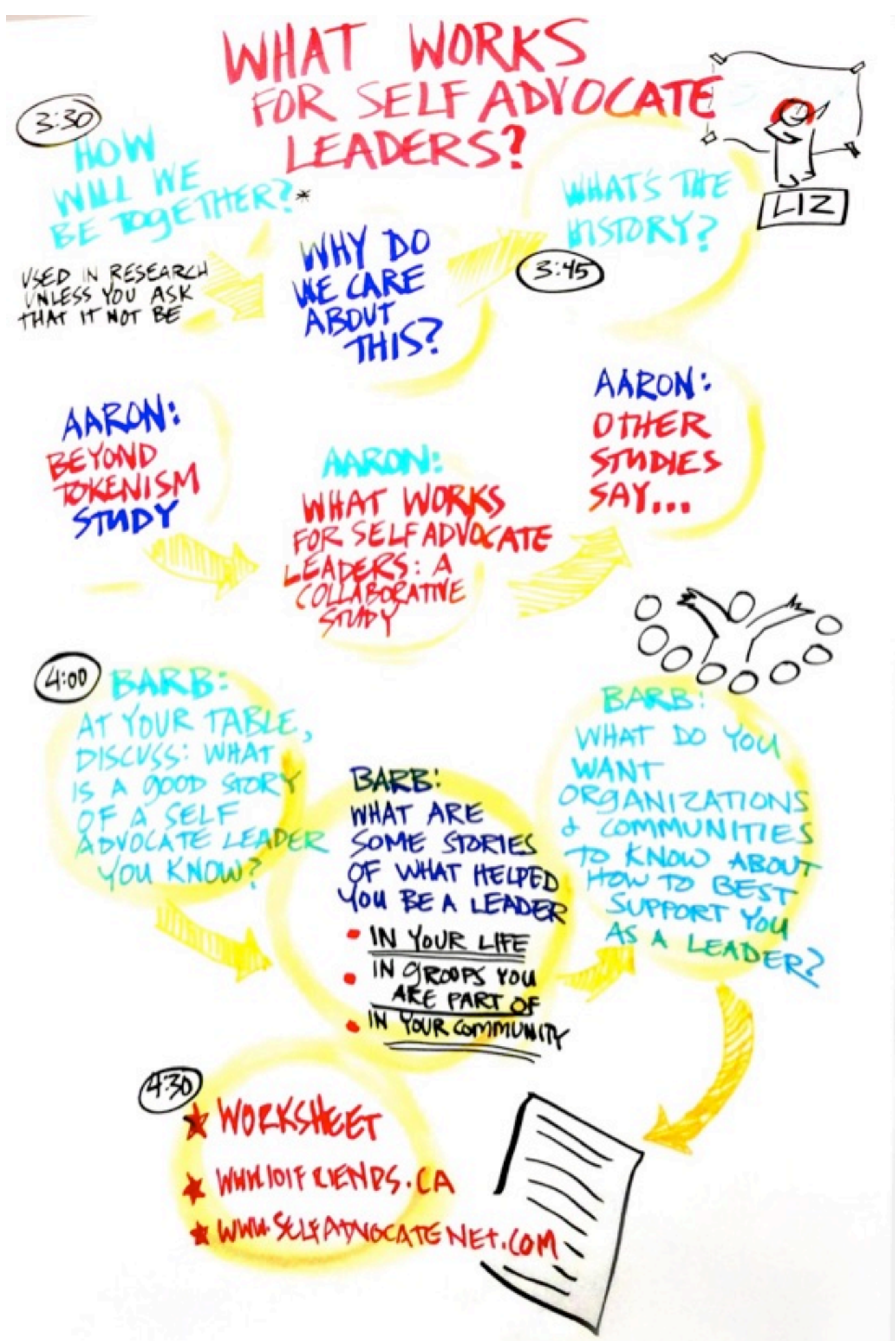


Figure 28. The flow of workshop agenda that was used in community conversations as a poster to introduce our topics and questions.

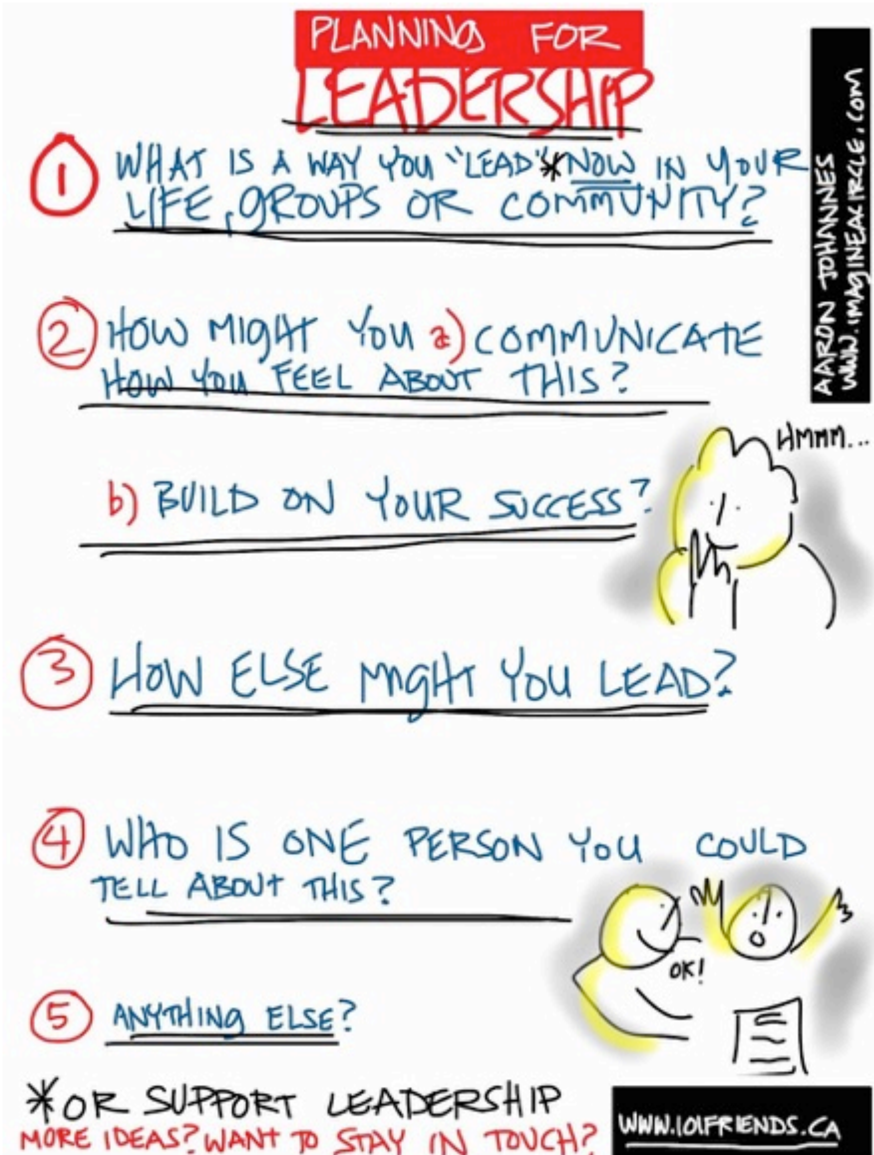


Figure 29. Graphic worksheet for participants to fill out after discussion, take home to their communities and share with allies and peers.

Analysis of Preliminary Data

Preliminary data from these informal community conversation workshops, in the form of graphic recordings, notes taken during and after events, and conversations with co-facilitators were broken down into meaning units. These were then analyzed thematically using principles of grounded theory (Glaser, 2009) and Stebbins's (2001) concept of useful community research on small "pockets" of people with shared concerns through a relationally focused social constructionist research lens (McNamee, 2014). Graphics allowed large amounts of data to be viewed and organized, and for

themes to emerge (Mullen, 2013; Mullen & Thompson, 2013; Tyler, Valek, & Rowland, 2005), with the aim of representing the priorities of the community conversation participants, giving them "voice" in the inclusive research (Walmsley & Johnson, 2003).

As themes emerged, we returned to the graphics and our notes and the memories of the self-advocate co-facilitators, for confirmation and expansion. Ideas which had seemed granular became seven main themes:

1. Leadership as an activity.
2. Leading together "in a circle."
3. Marginalized leadership as rhizomatic.
4. The functions of storytelling.
5. Accommodations and communication aids to support inclusion of all kinds of leaders.
6. Adult education strategies.
7. Magic/whimsy.

Meta Circle Reflection

These seven themes were brought into a "meta circle" reflection of experienced leaders with ID. This group represented the three largest and most influential self-advocate groups in British Columbia, as well as having experience on a national and international level. Members had been involved in the self-advocacy movement from 2 to more than 40 years. This discussion was also graphically recorded.

First, the meta-circle agreed these themes, except for the idea of "magic/whimsy," reflected their experiences of self-advocate leadership. Their ensuing discussion of the seven thematic categories forms the body of this research.

Review of Pertinent Literature

Two concurrent literature reviews for different audiences were part of this research project. First, a relatively traditional literature review gave a sense of literature and research concerning people with ID and leadership in context and identified gaps in the research (Johannes, 2017). Second, involved collaborators requested a sense of the

existing literature and research on self-advocate leadership and to know what would be useful to them. They were excited about the idea of access to this body of information. To this end, we looked at seven things that had been learned from five research projects to give them a sense of what had already been researched and discovered.

A body of literature related to leadership and disability was examined in an annotated literature review in an effort to contextualize this research (Johannes, 2017). Works related to leadership were divided into the following categories: research on leadership, research on variations of leadership in the lives of self-advocates such as self-determination, self-advocacy groups and community group inclusion, critical disability studies and adult education. Three authors served as a touchstone for this research: Hersted and Gergen's (2013) *Relational Leading: Practices for Dialogically-Based Collaboration,* De Pree's, *Leading Without Power: Finding Hope in Serving* (De Pree, 1997) and Palmer's *Healing the Heart of Democracy: The Courage to Create a Politics Worthy of the Human Spirit* (Palmer, 2011). Of these, Palmer's (2011) work was particularly important. Palmer (2011), coming from a Quaker tradition through a filter of psychology, political science, and social justice, theorizes that leadership has these five attributes:

- An understanding that we are all in this together;
- An appreciation of the value of "otherness";
- An ability to hold tension in life-giving ways;
- A sense of personal voice and agency, and
- A capacity to create community. (Palmer, 2011, pp. 172–173)

All of these works make a case for leadership as constituted by the qualities and processes of self-advocate leaders.

Accessible literature review.

Five works were identified to give a brief overview of the literature on leadership and ID that exists and these also provided an opportunity to discuss inclusive research methods in the community conversation workshops. Participants' interest at times led to further questions and dialogue:

1. “The Money, Friends and Making Ends Meet Research Group” was a group of researchers with ID who asked, how are we getting by on not enough money? In their research they discovered a network of interdependent self-advocates, helping each other out in ways that were more reliable than they realized. As they tracked their budgets together they realized many of them regularly spent money on gifts to put away in hopes of one day meeting the children who had removed from their homes (Inclusive Research Network, n.d.);
2. Griet Roets’s (2009) “Unravelling Mr. President's nomad lands: travelling to interdisciplinary frontiers of knowledge in disability studies,” rethinks what research on the lives of leaders with ID might be and how it might be reported. Participants were interested to hear about Roets as the advisor to Robert, president of his local self-advocate group and his journey of supported self-discovery to the goal of getting new glasses; in different environments, with different companions, he is seen to have different forms and levels of self-determination and power;
3. Dan Goodley’s (2000) *Self-Advocacy in the Lives of People with Learning Difficulties: the politics of resilience*, about the theme of resilience as perceived in the lives of self-advocate leaders and the necessity of their involvement if one is to develop policies and supports to serve their autonomy;
4. “Beyond Tokenism,” a contemporary study of self-advocate inclusion as participating leaders was sponsored by Michigan Developmental Disabilities Council and supported by Drs. Mark Friedman and Ruthie-Marie Beckwith in 2013. In this study, people with disabilities wanted to ensure their collaboration was effective and healthy by looking at what worked within one kind of leadership group;

5. *People First: Advice for Advisors* Bill Worrell's (1988) documentation of a collaborative project with People First of Canada to write the first book about processes which would support the leadership of people with disabilities.

This overview of these works gave participants a sense of the involvement people with ID have had in research, the kinds of questions being asked and the processes being used. Participants were far less interested in the works of authors dealing with typical leadership. From these five research projects, seven ideas demonstrated the usefulness of research like that in which they were currently participating:

1. Self-advocates should receive and share information in predictable ways with as much time as they need to understand (Friedman & Beckwith, 2014);
2. A self-advocate on a board or committee will be more likely to be successful and comfortable if they are two or more self-advocates involved Friedman & Beckwith, 2014);
3. People with complex issues are able to be leaders too (Friedman & Beckwith, 2014);
4. Leadership opportunities occur at different levels for self-advocate leaders in relation to where they are and who they are in relationship with (Roets, 2009);
5. Resiliency is a feature of self-advocate leaders (Goodley, 2000);
6. The temptation of advisors, helpers, and allies to be helpful often means the voices of self-advocate leaders are silenced, despite everyone having good intentions. It can be very hard to tell people who are helping you that what they are doing is not helpful (Goodley, 2000; Worrell, 1988);
7. There is a great deal we don't know about the lives of people with ID and research can help us see we are not alone and that there are things which are unfair which need to be addressed (Inclusive Research Network, n.d.).

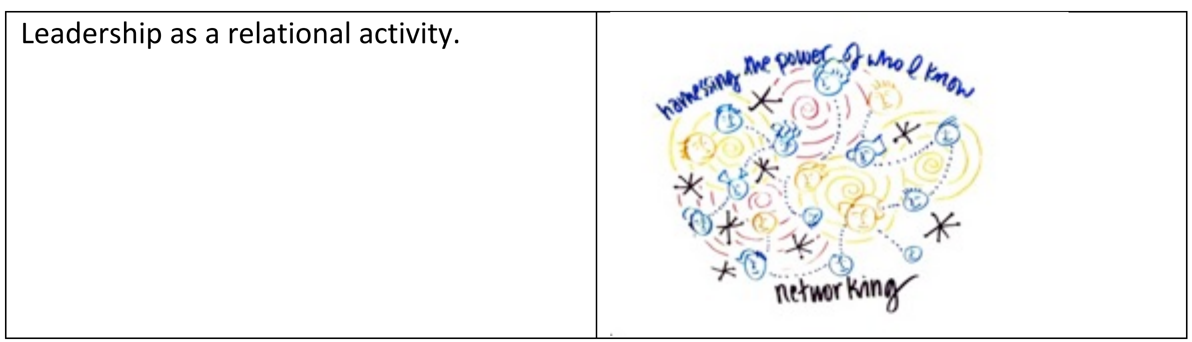
As an example of how research works, we discussed the second of these learnings using the example of co-facilitator Barb Goode's history of advising

organizations that there needed to be more than one self-advocate involved on a board or in a decision making group. However, when we looked we found no research to support this. It was an idea she intuited from her own experience. However, the "Beyond Tokenism" research (Friedman & Beckwith, 2013) gathered information from hundreds of inclusive boards and found this a common, important idea, which could potentially change the practices of inclusive decision making bodies. Participants thought we should just have trusted Barb's perception in the first place, but understood the process.

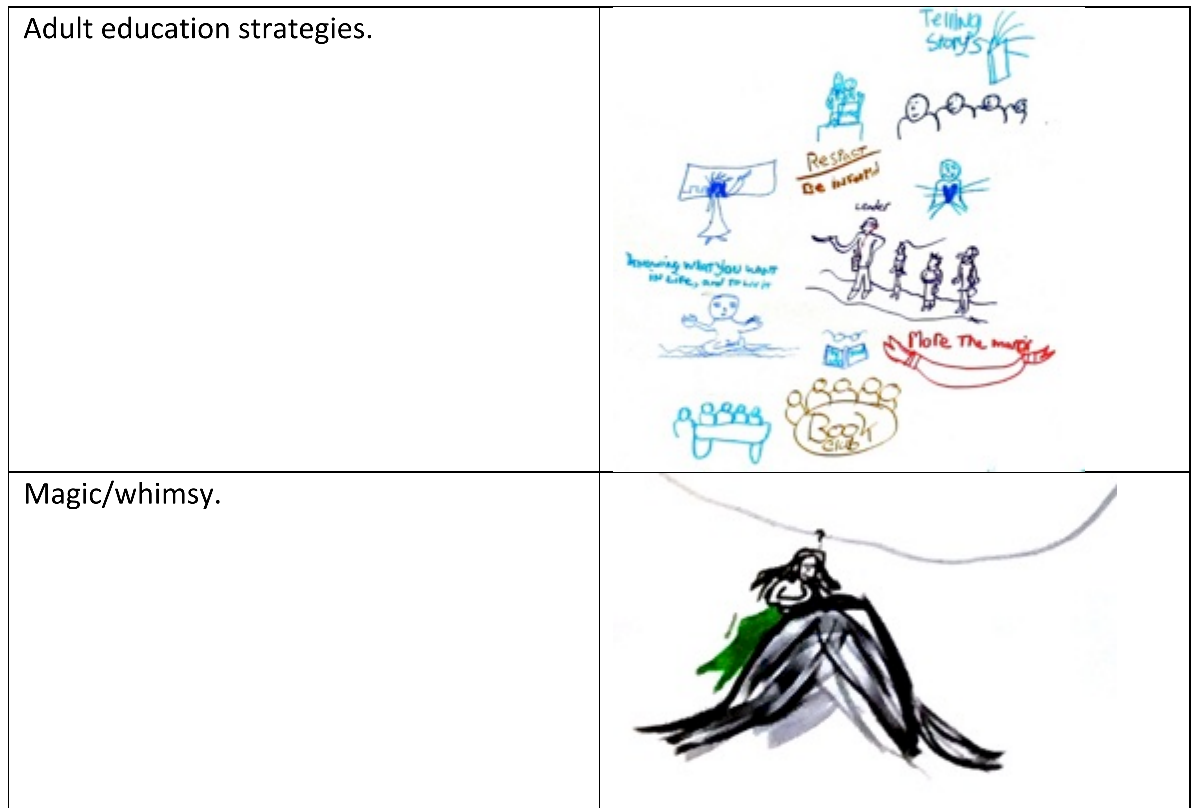
Findings: Themes

Figure 30. Graphic recording, focus group, meta-circle of leaders' discussion: Liz Etmanski and Aaron Johannes, July 26, 2016.

The following seven main themes arose during the community conversations:

Leadership as a relational activity.	

Leading together “in a circle.”	
Marginalized leadership as rhizomatic.	
The functions of storytelling.	
Accommodations and communication aids to support inclusion of all kinds of leaders.	



Adult education strategies.	
Magic/whimsy.	

Leadership as a relational activity.

A theme for self-advocate leaders in the community conversations was the importance of relationships, with each other and with allies, such as family members and employers, and with other inclusive groups they were part of. These relationships often supported people with ID to learn, be heard, have influence and find opportunities:

- "Having someone to believe you, having someone to look up to – it's the biggest gift in the world. We need to have people out there who really believe in you and look up to you. It comes from inside you. Like morals."

An important factor in such relationships was reciprocity and consideration for how others might be supported and what their goals might be:

- "If you care about other people you're a leader."
- "I've experienced a lot – I enjoy going to conferences – one of the things I like is hearing what people's goals are."

If relational supports were preferred and sometimes necessary, they required negotiation:

- "The thing that interests me and what I want to talk about is how we want to do things on our own and be leaders, but we also need help and we know we need help – and how do we balance those things?"
- "Yes, sometimes two things is a lot to juggle!"
- "We say we want voices but we need help, but when we get amalgamated with others we don't get listened to as much. Why are we so last on the list?"

Leading together "in a circle."

Participants in each of the different community conversations talked about leadership as moving forward together:

- "You gotta have responsibility; if you're going to say something you have to know what you're going to get on with . . . things can happen. We all have to be together with this. Not one person running the group. All of it has to be on the same page – working with it. Everyone's responsible."
- "For me, I have always said I don't see myself as a leader – I could be the person at the front of the room and that doesn't make me feel like a leader either – I am speaking for what I believe in and who I believe in, and that is that everyone has a voice."

A more traditional, heroic vision of leadership was, in fact, perceived as just another label:

- "It's up to us to be able to teach people they might not see themselves as a leaders. People have this idea about what a leader is. And they have this idea that we are leaders, like that."
- "Yes, when did that happen? We were just trying to help out! When did that become a thing, to be a leader? Who had the idea that there would be a person labeled as the leader?"
- "Yes, it's not like we have a price-tag stuck on our forehead!"

Marginalized leadership as rhizomatic.

Given that people with ID do not have many of the opportunities to lead as others, their ways of finding opportunities might be called rhizomatic. They maintained relationships that might be important to them and then tapped those when there were new opportunities in a kind of nomadic preparedness (Braidotti, 2011). In the community conversations, people had many examples of politicians and people of influence they had met, who became important allies. The meta-circle agreed that this networking was a common theme in their leadership, but thought of it more as making friends. Similarly, they were attentive to opportunities and ideas from a variety of sources:

- "I want to make a difference in my community, and I think the way to do that is to be on the mayor's council. We have a lady who is blind on our council now. I want to be on the mayor's council for where I live on, [so applied to be on the council]."
- "[At a conference] there were different groups from different parts of the city – different kinds of disabilities . . . we heard about another group and decided to start our own to advise the [Parks and Recreation] council [about ID]."

The functions of storytelling for self-advocate leaders.

An important tool in self-advocate leadership was storytelling. "Telling a story is a good idea," one self-advocate leader summarized. Their understanding of the many different functions of storytelling was subtle and profound:

- "Storytelling matters because we want to have a good life. When I heard all these different stories . . . I was getting treated in counseling – when people are facing this . . . when we do the polite thing, [we don't tell stories, we don't get better]."

For this particular group of self-advocate leaders there was also an obligation to support those who did not have opportunities to speak for themselves:

- “Our stories are proving to our society we can speak up for ourselves, there are a lot of people out there who have trouble speaking up for themselves. Sitting around this table we are trying to put out a voice for others.”

There were many examples of the influence of the stories they told in a number of different environments:

- “I was on the Parks and Recreation committee and we made changes because of stories we told.”

An important function of storytelling was as a way to think about belonging, and one participant told an evocative story about moving from being a witness of stories to being a participant in a story:

- “We went to the top of the Empire State building, and I was looking down at the lights and every light was like a story and I was just excited to be there. Then, the next day I had a microphone in my hands [at a disability pride event] and I was looking at the audience and I was oh my goodness I was so surprised – I had become part of a story.”

An important aspect of storytelling was informing others about possibilities in the community:

- “Sharing a story is key. I shared a story about our book club at a conference, and it was amazing [no one knew that people with ID could be part of book clubs].”

In this case the participant conveyed to others that they might join a book club but also conveyed to the conference of librarians that people with ID were thoughtful readers.

Stories were used to support their advocacy work:

- “I did a story one time about what happened – when I was made fun of in a restaurant – we didn’t know what a lawyer was, or what court was – and I won that case; it became a commercial – I was honored by the person who asked me to tell the story . . . we hired people to do the acting.”

As one self-advocate leader said, “The stories get you the results.”

However, they were also aware of how the power of stories could be subverted. One function of stories was that the opportunities to share stories were themselves indicative of where power and control lay:

- "If people have a caregiver they might not get heard – their parents or their caregiver might take over."
- "They want what's best for you but sometimes they have assumptions about what you can't do. And they're paying the rent you have to abide by their rules."

Related to this, they were aware, confused and resentful of the ways in which their focus on stories as a tool to create conditions for change was sometimes misused by event organizers:

- "They wanted to have a story circle but they had no intention of it being useful."
- "Are you just listening for the sake of it? Is there an outcome? They got to put it out there, they got to do it. The stories are telling."
- "I keep asking agencies and groups if we tell you these stories will you use them to help the situations – to practice what you preach? To change things? Are they meaningful?"
- "I've seen people who are facilitating these events not taking notes – not doing anything just listening to stories – if you're not writing this down, getting this down on paper how do we know what you'll do with it. I asked this guy, and he said, 'Oh this isn't for our benefit this is for yours,' and I told him, no, this is a teaching event for you – we are trying to teach you."
- "Yes, if you can't do it right then get out of the way and let a disabled person show you what you're supposed to be doing – because nobody knows these disabled people better than the disabled people – do the job right."

Stories were also important ways for self-advocates to warn each other about potential dangers:

- "I got sent to Willow Clinic and I had heard stories. I never had to have a social worker before . . . I was struggling in my life. In the waiting area, I heard a bunch of noises. . . . People had told me stories and I thought is this going to happen to me now? Oh my god – will I get dragged by my hair? I was relieved not to go there. I haven't told many people about this. But now I feel free, I don't mind talking about it."

This led to a discussion of stories as history, the subject of a related paper (Johannes, 2017b): "I worry stories are being lost," said a self-advocate leader.

Accommodations and communication supports to support inclusion of all kinds of leaders.

Leaders in the meta-circle discussed communication and the need for accommodations such as plain language in sophisticated, articulate ways:

- "When you hear a big word you say what the hell does that mean – these professional people are supposed to help."
- "In the old days parents were supposed to speak for you" [but now,]
- "I can speak on my own and I have my own accomplishments."

They saw communicating differently as a way to organize exclusion:

- "There are two different things. One is perception. One is what services want. The perception that people can't speak. Their body language tells you – there is a system set up by it all – it is not right – it always been set up like this. The people [in systems] don't have an education; why this person is 'acting up' – or the caregiver [is creating the conditions for 'acting up' by not understanding] – a different perception."

They felt these considerations for receptive communication were particularly important issues for inclusive decision-making groups to consider:

- "If you believe in people being involved you have to put your money where your mouth is. That's the way to include people."
- "People might need different things to even get to a meeting – it is up to the board to say to people how can we make it easier for people to be involved?"

They acknowledged that some forms of communication in leadership groups might be harder than others. Financial statements were given as an example, but they also gave examples of financial statements they felt were easier to read and understand:

- "Sometimes [in organizations] the treasurer's report throws people off, we lose members, when do you say it when not . . . you lose their concentration real quick. We have to show it to them."
- "Yes – the treasurer's report, like the (name) Society [a graphic pie chart of expenses and incomes] – It's a simple report . . ."

Related to this, they agreed that some communication methods, such as conference calls, were difficult:

- "Speech pattern are different in person than on the phone – [we can read] body language."

In terms of expressive communication, they were knowledgeable about the uses of and need for augmentative and assistive communication programs:

- "People forget the conversation between verbal and nonverbal – everyone is verbal to a point. I walked over to someone's caregiver and said do you mind if I try to help? They said, sure, you try to make sense [of him]. He picked up a cup and threw it his caregivers and I said well that's one way to get their attention . . . so my point is there's more than one way to communicate."
- "They assume people aren't trying to say something but they haven't done any work to help them say what they mean . . . if they work if they learn to point at something."
- "There are different ways of speaking – eyes, hands, body language. Pictures are a thousand words."

If one important issue was the inclusion of people with more significant communication challenges, another was, as articulate members of decision-making groups, to be taken seriously themselves:

- "I'm tired of people thinking we can't talk about complicated things, I'm sick of it."
- "Take us seriously – we understood you."
- "We are credible."
- "Believable."
- "With great responsibility comes great power!"
- "There are two kinds of people – people who will listen and people who won't – some people really care but others are dismissive."

Adult education.

In the community conversation workshops participants often talked about the problems with their own educations within the school systems, the difficulty in finding appropriate education venues as adults, and their success when they did. It was difficult for them to feel confidence in their abilities to learn:

- "[When I started] this lady asked me to join this group and the only thing I could do was my laundry and I was going to this group to learn to speak up – I was only 13 – I brought my dad over to see what I could do to see if I could learn to do the things myself. [He did not think I could]."

Often messages of incapacity were communicated by what was embedded in policy or practices:

- "Ditto x 4 [about a greater need for boards that wanted to be inclusive to be responsible for communication]! I still can't answer why I don't see myself as a leader . . . if [disabled] people are on boards of agencies they might have to wait 2 years to vote [while non-disabled people get to vote as soon as they are elected]; I think everyone on a board should be treated the same."

However, there were many examples of experiential learning:

- "When I moved out I didn't know how to do anything – it was like a puzzle – I pay my own bills . . . I didn't know what I didn't know."

Some parts of accessing higher education were inaccessible for some for different reasons:

- "Wait lists – this scares people. They get frustrated, they don't even bother. It takes a while to understand. I went to hear native people – everyone is not the same."

The meta-circle felt there were issues around assumptions of the educational systems and a general misunderstanding that there might be different ways of thinking:

- "Even logic has structure – structure means stretching yourself . . . you learn through all the steps you've gone through . . . you learn to do the things you were not considered to be able to."

Magic/whimsy.

In reviewing the graphics from the community conversation, there were many magical, whimsical images such as Captain Hook, mermaids, communicating YouTube cats, superpowers, and so forth. In general a sense of fun felt important as part of self-advocate leadership culture. They agreed that their leadership culture was more fun, "A lot of people still want to know how we are so happy." However, the meta-circle objected to the idea that magic and whimsy was part of their culture:

- "One of the things I don't believe in is magic. My goal is to save money. I have a RDSP [Registered Disabilities Savings Plan] I deposit money – I transferred American money into my RDSP and I have 18,000 so far. . . I just turned 30 but I am thinking about when I retire."

For the most part, participants simply did not respond to this idea. When one participant suggested, "I am making magic by drawing," another responded, "She's learned to think beyond making sense" which seemed to indicate that she was using another kind of logic, but that it was neither whimsical or magical.

Other themes.

While the meta-circle group discussion was facilitated to address the seven themes that came up in the community conversation workshops, other themes arose as well. One of these was resilience, well documented by Goodley (2000):

- "I'm glad I never gave up, because I came close to giving up. A lot people out there are getting close to giving up – I am a come-back kid. I am fighting to continue to have a voice."
- "Two ways to spell can't one is C-A-N-T and the other way is C-A-N-2!"

The meta-circle gave examples of progress in the rights of people with ID. For example, the right to marry:

- "They didn't believe people should get married way back then . . . you had to break down new barriers."
- "When we got married people with disabilities weren't allowed to."
- "When we got married, my wife said why can't we just do what we want? Tears work."

However, there was also a sense of frustration with a lack of progress in the general social conditions of people with ID:

- "I went to the movie at a conference, with other self-advocates. It was Gilbert Grape – I remembered seeing it years ago and thinking this is what it's like, and now, years later, people are watching it, thinking this is what it's like."

One younger participant discussed a disability pride parade he had been part of:

- "I have a developmental disability and one of the things I've done – I just got back – I did a disability pride parade – there were over 5000 people and we had a banner and my mom and my dad are walking and I was waving – a banner about my work and my goals – and we ended in a huge square park. I enjoyed seeing everyone. Waving at everyone was one of the most amazing things I've experienced. I'm just so proud of who I am."

The older participants were excited by this story and said, "He is showing people with disabilities we can accomplish everything."

A final comment in the group was that there would always be the need for self-advocate groups, as long as there were parents' groups. Parents' groups were

considered to be most of the agencies and government projects, which had been started as parent initiatives. Participants offered the following statements:

- “The parents think they will listen to the [self-advocacy] group, not the parents if they go there.”
- “Parents can be very critical – [they make] some assumptions when people are trying to come together.”

Discussion

The meta-conversation about the themes that arose was useful in that it brought up new ideas and confirmed old ones. It demonstrated, among other things, that adult education for people with disabilities, often called “special education,” is a mostly unseized opportunity for the kind of change and growth that is common in contemporary adult life. In British Columbia it was only a decade or two ago that most adults with ID. spent their day housed in sheltered workshops, engaged in repetitive tasks which were assumed to be the limits of their potential. When this ended, for various reasons (Fuatal, 2016), no concerted better idea supplanted it. Adults with ID continue to be served by agencies embedded within a medical services model rather than an emancipatory educational model that might be more interested in their potential for change and growth. The evidence of their informed participation questions their lack of opportunities and what such a lack implies about their futures:

> *This emphasis [is social constructionism] on education as a making is optimally suited to the emerging global conditions of rapid change. The same technologies that generate a consciousness of construction are also responsible for the continuous circulation and accumulation of ideas, perspectives, and innovations. What we take to be knowledge about the world thus expands exponentially, while simultaneously undermining the credibility and often the utility of any taken-for-granted world. In effect, what we take to be known is always in motion. The challenge for future educational practices is preparing students for a life of continuous innovation – or knowledge making.* (Dragonas, Gergen, McNamee, & Tseliou, 2015, p. xii)

The methodology of the research is significant to the discussion of this paper given the lack of literature on ID and leadership and the involvement of self-advocates in its design. It was not at all challenging to involve people with ID in this research

project, and they contributed knowledgably to an iterative, diversity building methodology that worked for them and will be valuable to their allies.

This process was not without its tensions. Half way through the research project, as the accruing data was being analyzed and reviewed with two members of the advisory group, they became frustrated: “I don't understand all this “data” – I know you have to do things in a certain way to satisfy academics but we trusted you with our stories. That's the research, that's what we wanted.” Given the focus on “stories” from the beginning, the question was what was being misunderstood. The important realization was that an assumption had been made in thinking that the idea of “stories” was simply a way of equalizing the playing field. Further, their experiences of not being heard made them concerned that this would not be another case, and they needed reassurance. The perception that stories become, given repeated themes, narratives (Hagel, 2011) was perceived as refurbishing them for academic purposes. There was a realization that while putting stories together into narrative-based thematic data is a usual academic methodology in qualitative studies, the “pure” story that is owned by the person and shared in these conversations must remain intact. To that end, it was confirmed that people's actual language would be used in combination with graphically recorded images of their participation in conversations. There was agreement that graphic recording is, in itself, a proven way to demonstrate that one is hearing the actual story as one draws it and anything that has been misheard can be corrected at the moment and was. This satisfied the project advisors.

Measuring success.

Success of this social constructionist research project must be measured in three ways. First, self-advocate colleagues wanted to know whether this could be an effective way of gaining insights into their leadership. Second, did self-advocate colleagues gain mastery over research processes? Throughout, sessions were planned and organized by self-advocate facilitators and graphic recorders who, by the last community conversation, did half of the facilitation and half the graphics. Third, was the objective of

producing a body of information that would be useful academically and to the self-advocate community met?

Groups such as SelfAdvocateNet, which provides online information to groups around the province about events and projects through social media, repeatedly asked for updates and to be involved. Conference workshops led to invitations to facilitate other community conversations to foster self-advocate leadership, each of these involved a local self-advocate co-facilitator. There were frequent requests for updates from participants in the workshops and also updates on the effect their "planning for leadership" worksheet had in their local communities. These were indicators of the excitement and sense of ownership of the British Columbia self-advocate community, which was generated by the project. We also attended an academic conference poster session during which self-advocates discussed our findings so far with an international group of attendees. After analysis, the draft paper was translated into a number of forms with people with disabilities to make it accessible through plain language, graphics, discussion, and social media to fulfill the promise of bringing back the information to the community.

Perhaps most unexpectedly, participants were moved to further involvement in community leadership. The participant who applied to be part of a civic leadership group was welcomed there, another participant joined a community group for senior leaders which responded by requesting that she do a workshop on inclusion for them, and another went on to speak and lead workshops on her own.

In this narrative research, stories were the preferred methodology for research collaborators and participants. Their intuition, and evidence, that stories are important is balanced by their frustration about how their stories have been used or are ignored (Pitonyak, n.d.). Hagel (2011) discusses the need for "a compelling narrative" (Examples of Narratives section, para. 2) in organizational and social change, and self-advocates have acted on this in intuitive ways:

> *A narrative has two key elements. First, it's open ended – it's driven by some view of an opportunity or threat out in the future that has yet to be achieved and it's far from guaranteed that it will be achieved, but it is worth pursuing. Second, it's*

> *ultimately not about you, it's a call to action directed to the people you are wanting to reach – it motivates them to collaborate with you in ways that will help all of you to achieve something that's really valuable.* (Hagel, 2011, Crafting a Personal Narrative section, para. 2)

For example, participants with ID responded with excitement to Roets's (2009) paper, "Unravelling Mr President's nomad lands: Travelling to interdisciplinary frontiers of knowledge in disability studies." They were entranced and excited about the completeness of recording a multiplicity of leadership contexts that resonated with their own lives, even though written about people on the other side of the world in a country they barely knew about.

The roles of self-advocate leaders are more complex than might be imagined, if their presences are to be authentic. Some concrete ideas for practice arising from this research and the literature review:

- Involve more than one self-advocate in any group of participating leaders;
- Consistently utilize accommodations that work for the person, such as graphic recording, meeting ahead of time, large print, plain language, support persons who stay with them, etc.;
- Have the same rules for self-advocate leaders as any differences may be interpreted as predictive that they are less competent;
- Assume competency.

Some new, more subtle ideas about leadership within self-advocate culture were also significant within this research:

- Self-advocate leaders may have a significantly different understanding of what leadership is than what others might assume;
- Self-advocates may want to make decisions together informed by their peers, "in a circle," so decision making they are unprepared for will be more difficult;
- They feel this responsibility of speaking particularly for those with communication challenges strongly;

- Leadership partners may want to depend on their relational abilities to leverage shared causes;
- Storytelling, a powerful organizational tool, can be a strength of self-advocate leaders in inclusive leadership groups, and this strength may lend itself to crucial spokesperson roles;
- Storytelling may be a way to initiative and conduct decision-making conversations;
- Assume a history of disenfranchisement prior to one's interactions and address it to create a clear path towards shared goals with self-advocate participants.
- Make a habit of debriefing all initiatives in a way that leads to increased learning and mastery.

The difficulty, then, is the tightrope between academic practices and individuals I am known by, who are supported by their networks which I might or might not be part of. Throughout my research, responses from every part of the disability related community were excited. "How do we lead?" "How do we support authentic self-advocate leadership in our organizations?" "How do we support our children to be decision makers?" "How might we included people with intellectual disabilities in our research?" As the late Arnold Bennington liked to say, "This is a story everyone will want to hear."

Allies who have come to respect the leadership abilities of people with intellectual disabilities continued to accrue, often through their own experiential learning. Self-advocate leader Tia Nelis recounts that Justin Dart, a hero of the disability rights movement, "didn't think people with cognitive disabilities could do a good meeting and be successful at organizing until he came to the national group" (Nelis & Caldwell, 2007, p. 20). After meeting with them he said that, out of "many, many meetings, even with people who worked in the White House . . . [he] had never seen a meeting more organized" (Nelis & Caldwell, 2007, p. 20). Despite evident successes in leadership there continues to be an assumption that they do not have the capacity to

participate in decision-making, as evidenced by decisions such at that made in British Columbia to not include them on the board of C.L.B.C. (Stainton, 2009).

The evident plasticity of the lives of people with disabilities in popular media is striking, with discussions ranging from whether people should have a choice about whether they live in a nursing home or the community (O'Connell, 2016) to their continued placements in homes that are repeatedly deemed harsh and abusive (Vogell, 2016) to their successful entrepreneurial ventures (Szathmary, 2016) to their fierce advocacy against right-wing leaders (Shriver, 2012). In few other areas of the lives of people with disabilities is this plasticity so apparent as in the study of how they lead, in their lives, in the groups they are part of and in their communities. For example, during the course of this research I supported a 76-year-old self-advocate leader who had received a life achievement award for effective public advocacy who, on returning to his home, was told by his caregiver that his "allowance" had been reduced. They wanted him to learn the "natural consequence" of having loaned money to his girlfriend. I found out about this when he felt faint because he had not eaten during our 12-hour workday.

Locally, in British Columbia, the prevailing issues appear to be much the same as those that appear globally. The hungry leader awarded in one place and treated like a child in another has counterparts in Griet Roet's (2009) paper. People with disabilities are not included, or their stories are not heard or not believed (Malacrida, 2006), or they are included, but feel tokenized (Friedman & Beckwith, 2013).

At its most extreme the implications of a lens of leadership, etymologically derived from the Latin "to go forward," has implications for arguments such as Peter Singer's (as cited in Tillman, 2013) claim that "personhood" (p. 18) be reserved for "those beings that have enough cognitive capacity to project themselves into the future" (p. 18), making extermination of those who are perceived as not having this quality morally possible. Leadership occurs within a vision of the future, and to "go forward" is to project oneself there.

Some few studies look at what best serves this kind of inclusion (Friedman & Beckwith, 2013), but these often come with assumptive questions. Friedman and

Beckwith's (2013) important and singular Beyond Tokenism study, for example, looks at the roles people with disabilities play in the boards and governance committees that make decisions about their lives, but it assumes there is a potential "fit" and that these are important roles for social change. However, it might also be said that such organizations have always held back the potential emancipation of people with disabilities and that such involvement is more of a distraction than empowerment.

British Columbia, which has been a leader in inclusion, is a good example given well-meaning initiatives to include self-advocate decision makers on boards, in government and as employees. These have, in fact, led to a reduction in the potential of the self-advocate movement as almost every one of these positions requires signing or at least investing in an agreement to not publically disagree with the organization one is part of. Often crucial gaps are missed in understanding these inclusion initiatives – for example, the ongoing and embedded poverty of many people with intellectual disabilities makes it impossible for them to refuse potential work even if it means they cannot continue to advocate for their peers. In this study, an open-ended collaborative approach allowed people with disabilities to be part of a dialogic process that led to a final focus group discussion of issues that were important to them.

Throughout this research project people with disabilities and those who support them were excited to learn how leadership worked for them, and they "owned" the research project.

Limitations and Future Research

Their long, successful tradition of leadership in self-advocacy groups and in some organizations has been barely examined from an ethnographic and appreciative perspective in terms of what works best for people with disabilities. While leadership is identified as a crucial area for learning, a survey of special educators found almost no experiential learning in schools, leading Carter et al. (2011) to state that leadership is "perhaps the least explored and understood aspect of self-determination among individuals with disabilities" (pp. 57–58).

One limitation of this research was that the focus group was made up of people who would be considered to be articulate and thoughtful leaders who were experienced at being the person at the podium at the front of the room. Of the nine participants included there was an ex-President of People First of Canada, an ex-President of B.C. People First, the treasurer of B.C. People First, the leader of a local self-advocacy group who also worked in advocacy professionally, and two successful entrepreneurs. In our planning this was mitigated by the inclusion of two other participants, one of whom used an augmentative communication device and another who often appears to have echolalia. However, the one was unable to attend, and the other, rather than demonstrating echolalia that day turned out to be perhaps the most articulate, well-spoken members of the focus group. When someone asked how he was doing this, he said, “You keep inviting me to these interesting things.”

There is much room for future research, particularly that which arises from self-advocate generated questions about their own lives, services and supports. Researching such questions in other localities to compare results would give a broader picture of what is working in other places. Specific questions to research further would be about the relationship of articulate self-advocates to those who are less capable of communicating their needs, and the relationship between parents’ groups and self-advocate groups.

Some members of this advisory group stated they would be interested in being part of an ongoing inclusive research group, to learn more about these skills themselves and to be of benefit to their communities.

Conclusion

A slowly growing body of work such as the Beyond Tokenism project (Friedman & Beckwith, 2014) and the work of Goodley and others (Goodley, 2000, 2005; Roets, 2008; Simplican, 2015; Wehmeyer, 2013) have begun to give us a better sense of the numbers of self-advocate leaders, their activities, their lives and how they work best.

These informal conversations about leadership, leading to the self-advocate generated topics of the focus group, demonstrate further clarity about their perceptions

on how to best support their inclusion as leaders. Often these ideas are in contrast to roles and supports within governmental systems which depend on what Simon Duffy (2016) has referred to as “confusopoly” (para. 1), a state which thrives where there are few real choices beyond the offered options, little to distinguish one service from another, and few real competitors.

References

Ashby, C., Jung, E., Woodfield, C., Vroman, K., & Orsati, F. (2015). 'Wishing to go it alone': The complicated interplay of independence, interdependence and agency. *Disability & Society, 30*(10), 1474–1489. doi:10.1080/09687599.2015.1108901

Beresford, P. (2003). *It's our lives: A short theory of knowledge, distance and experience*. Victoria, Canada: Open Services Project.

Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 27*(1), 3–12. doi:10.1111/jar.12083

Braidotti, R. (2011). *Nomadic theory: The portable Rosi Braidotti*. New York, NY: Columbia University Press.

Buchanan, I., & Walmsley, J. (2006). Self-advocacy in historical perspective. *British Journal of Learning Disabilities, 34*(3), 133–138. doi:10.1111/j.1468-3156.2006.00410.x

Caldwell, K. (2013). Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research, 14*(4), 488–507. doi:10.1177/1468794113490718

Caldwell, K., & Nellis, T. (n.d.). *The future of dyadic interviewing*. Retrieved from http://conference.tash.org/sessions/the-future-of-dyadic-interviewing/

Carter, E. W., Swedeen, B., Walter, M. J., Moss, C. K., & Hsin, C.-T. (2011). Perspectives of young adults with disabilities on leadership. *Career Development for Exceptional Individuals, 34*(1), 57–67. doi:10.1177/0885728810387411

Chenoweth, L., & Clements, N. (2011). Participation opportunities for adults with intellectual disabilities provided by disability services in one Australian state. *Journal of Policy and Practice in Intellectual Disabilities, 8*(3), 172–182. doi:10.1111/j.1741-1130.2011.00307.x

De Pree, M. (1997). *Leading without power: Finding hope in serving community*. San Francisco, CA: Jossey-Bass.

Dragonas, T., Gergen, K. J., McNamee, S., & Tseliou, E. (2015). Education as social construction: An introduction. In T. Dragonas, K. J. Gergen, S. McNamee, & E. Tseliou (Eds.), *Education as social construction: Contributions to theory, research and practice* (pp. ix–xxiii). Chagrin Falls, OH: Taos Institute/WorldShare Books.

Duffy, S. (2016, August 3). *Confusopoly – lessons for social change*. Retrieved from http://simonduffy.blogspot.ca/2016/08/confusopoly-lessons-for-social-change.html

Feduck, M. (2012). *It's about time: The significance of the centre block demolition for former residents of the Woodlands institution* (Master's thesis, University of British Columbia). Retrieved from https://open.library.ubc.ca/cIRcle/collections/ubctheses/24/items/1.0073228

Friedman, M., & Beckwith, R.-M. (2013). *National study, beyond tokenism: Executive summary*. Retrieved from http://www.beyondtokenism.com/wp-content/uploads/2016/05/BeyondTokenismExecutiveSummary-final.pdf

Friedman, M., & Beckwith, R.-M. (2014). *Easy read results of the national study on supporting people with complex needs in leadership roles*. Retrieved from http://www.beyondtokenism.com/easy-read-results-of-the-national-study-on-supporting-people-with-complex-needs-in-leadership-roles/

Fuatal, T. (2016, April 12). From exploitation to employment: Undoing Canada's sheltered workshop system. *Rabble.ca.* Retrieved from http://rabble.ca/news/2016/04/exploitation-to-employment-undoing-canadas-sheltered-workshop-system

Fyson, R., & Fox, L. (2014). Inclusion or outcomes? Tensions in the involvement of people with learning disabilities in strategic planning. *Disability & Society, 29*(2), 239–254. doi:10.1080/09687599.2013.776491

Fyson, R., & Simmons, K. (2003). Strategies for change: Making valuing people a reality. *British Journal of Learning Disabilities, 31*(4), 153–158. doi:10.1111/j.1468-3156.2003.00251.x

Garrucho, K., Barry, J., Malatest, R., & Chou, P. H. (2013). *Include me! Quality of life initiative: Technical report.* Retrieved from http://www.communitylivingbc.ca /wp-content/uploads/Include-Me-Technical-Report-and-Update-June-2013.pdf

Gergen, K. J. (2015a). From mirroring to world-making: Research as future forming. *Journal for the Theory of Social Behaviour*, *45*(3), 287–310. doi:10.1111/jtsb.12075

Gergen, K. J. (2015b). From propositions to practice pedagogy for life as process. In T. Dragonas, K. J. Gergen, S. McNamee, & E. Tseliou (Eds.), *Education as social construction contributions to theory, research and practice* (pp. 49–61). Chagrin Falls, OH: Taos Institute Publications/WorldShare Books.

Glaser, B. G. (2009). *The discovery of grounded theory: Strategies for qualitative research.* New York, NY: Transaction.

Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties: The politics of resilience.* Berkshire, United Kingdom: Open University Press.

Goodley, D. (2005). Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities, 9*(4), 333–343. doi:10.1177/1744629505059267

Hagel, J. (2011, May). *The pull of narrative – in search of persistent context*. Retrieved from http://edgeperspectives.typepad.com/edge_perspectives/2011/05/the-pull-of-narrative-in-search-of-persistent-context.html

Hersted, L., & Gergen, K. J. (2013). *Relational leading: Practices for dialogically based collaboration* [Electronic version]. Retrieved from https://www.amazon.ca /Relational-Leading-Practices-Dialogically-Collaboration-ebook/dp/B00CAAS89I /ref=sr_1_1

Inclusive Research Network. (n.d.). *Money, friends and making ends meet research group.* Retrieved from http://www.inclusiveresearch.net/completed-research/money-friends-and-making-ends-meet-research-group/

Johannes, A. (2013). *People with intellectual disabilities as leaders: Collaboratively identifying strategies for success, using graphic facilitation* (Master's thesis). Athabasca University, Canada.

Johannes, A. (2017b). *Literature review – intellectual disability and leadership*. Unpublished manuscript.

Johannes, A. (2017d). *A meta-circle of leaders with intellectual disabilities discuss what is helpful in the leadership of their lives, the groups they are part of and in their communities.* Unpublished document.

Kitchin, R. (2000). The researched opinions on research: Disabled people and disability research. *Disability & Society, 15*(1), 25–47. doi:10.1080/09687590025757

Malacrida, C. (2006). Contested memories: Efforts of the powerful to silence former inmates' histories of life in an institution for 'mental defectives.' *Disability & Society, 21*(5), 397–410. doi:10.1080/09687590600785720

McNamee, S. (2014). Research as relational practice: Exploring modes of inquiry. *Systemic Inquiry: Innovations in Reflexive Practice Research*, 74–79.

Mullen, K. C. (2013). *I see what you mean: Visual and participatory climate change communication.* Department of Human Dimensions, Natural Resources, Colorado State University.

Mullen, K. C., & Thompson, J. L. (2013). Graphic recording: Using vivid visuals to communicate climate change. *The Electronic Journal of Communication, 23*(3). Retrieved from http://www.cios.org/www.cios.org/EJCPUBLIC/023/3/023034 .html

Nelis, T., & Caldwell, J. (2007, November 25). *Tia Nelis*. Retrieved from http://digitalassets.lib.berkeley.edu/roho/ucb/text/nelis_tia.pdf

North Dakota Studies. (n.d.). *The history and culture of the Standing Rock Oyate.* Retrieved from http://www.ndstudies.org/resources/IndianStudies /standingrock/leaders_traditional.html

O'Connell, K. (2016, May 25). New law could force states to let people with disabilities live independent lives. *TruthOut News.* Retrieved from http://www.truth-out.org/news/item/36162-new-law-could-force-states-to-let-people-with-disabilities-live-independent-lives

Palmer, P. (2011). *Healing the heart of democracy: The courage to create a politics worthy of the human spirit* [Electronic version]. Retrieved from https://www.amazon.ca/Parker-Palmer-Healing-Heart-Democracy/dp /B00RWOBMN6/ref=sr_1_3

People First of Canada. (n.d.). *People First of Canada.* Retrieved from http://www.peoplefirstofcanada.ca/

Pitonyak, D. (n.d.). *Who holds your story?* Retrieved from http://www.dimagine.com /WhoHoldsYourStory.pdf

Qualtrough, C. (2016, June 22). *Minister Qualtrough's announcement on an engagement process that will inform planned accessibility legislation*. Retrieved from https://www.canada.ca/en/employment-social-development/news/2016/06 /minister-qualtrough-s-announcement-on-an-engagement-process-that-will-inform-planned-accessibility-legislation.html

Riddington, C. (2012). Ten years of partnership. *Tizard Learning Disability Review*, *17*(1), 14–21. doi:10.1108/13595471211207093

Roets, G. (2008). *Connecting activism with academia: A postmodernist feminist perspective in disability studies* (Doctoral dissertation, Ghent University). Retrieved from https://biblio.ugent.be/publication/4167118

Roets, G. (2009). Unravelling Mr President’s nomad lands: Travelling to interdisciplinary frontiers of knowledge in disability studies. *Disability & Society, 24*(6), 689-701. http://dx.doi.org/10.1080/09687590903160142

Shriver, T. (2012, October 23). *Open letter to Ann Coulter*. Retrieved from https://specialolympicsblog.wordpress.com/2012/10/23/an-open-letter-to-ann-coulter/

Simplican, S. C. (2015). *The capacity contract: Intellectual disability and the question of citizenship*. Minneapolis, MN: University of Minnesota.

Stainton, T. (2009, November 27). Liberals betray citizens with developmental disabilities by continuing lack of consultation. *Vancouver Sun.* Retrieved from https://www.pressreader.com/canada/vancouver-sun/20091127/281736970543964

Stebbins, R. A. (2001). *Exploratory research in the social sciences* (Qualitative Research Methods Vol. 48). Thousand Oaks, CA: Sage.

Szathmary, Z. (2016, January 25). 'I got hit by the love bug': America's only Down syndrome restaurant owner to close and move closer to his girlfriend after meeting her at a special needs forum. *DailyMail*. Retrieved from http://www.dailymail.co.uk/news/article-3414789/I-got-hit-love-bug-America-s-syndrome-restaurant-owner-close-closer-girlfriend-meeting-special-needs-forum.html

TASH. (2015). *Speakers and sessions*. Retrieved from https://2015tashconference.sched.org/event/4ApG/what-works-self-advocate-leadership-in-life-groups-and-community

Tillman, R. (2013). Ethical embodiment and moral reasoning: A challenge to Peter Singer. *Hypatia, 28*(1), 18–31. doi:10.1111/j.1527-2001.2011.01242.x

Tyler, C., Valek, L., & Rowland, R. (2005). Graphic facilitation and large-scale interventions: Supporting dialogue between cultures at a global, multicultural, interfaith event. *The Journal of Applied Behavioral Science*, *41*(1), 139–152. doi:10.1177/0021886304272850

United Nations. (n.d.). *Convention on the rights of persons with disabilities and optional protocol.* Retrieved from http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

United Nations. (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-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

Vancouver Sun Editorial Board. (2016, June 15). Editorial: Knock down disability barriers. *The Vancouver Sun.* Retrieved from http://vancouversun.com/opinion/editorials/editorial-knock-down-disability-barriers

Vogell, H. (2016, June 24). Florida cracks down on troubled for-profit facility for people with disabilities. *ProPublica.* Retrieved from https://www.propublica.org/article/florida-cracks-down-on-troubled-for-profit-facility-for-the-disabled

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures.* London, United Kingdom: Jessica Kingsley.

Wehmeyer, M. L. (2013). The story of intellectual disability: An evolution of meaning, understanding, and public perception. Baltimore, MD: Paul Brookes.

Wolfensberger, W. (1994). The growing threat to the lives of handicapped people in the context of modernistic values. *Disability & Society, 9*(3), 395–413. doi:10.1080/09687599466780421

Worrell, B. (1988). *People First: Advice for advisors.* Downsview, Canada: National People First Project.

Chapter 6:

Röd tråd: A Parallel Story of Leadership as the Discovery of Self, Other, and History – An Autoethnography

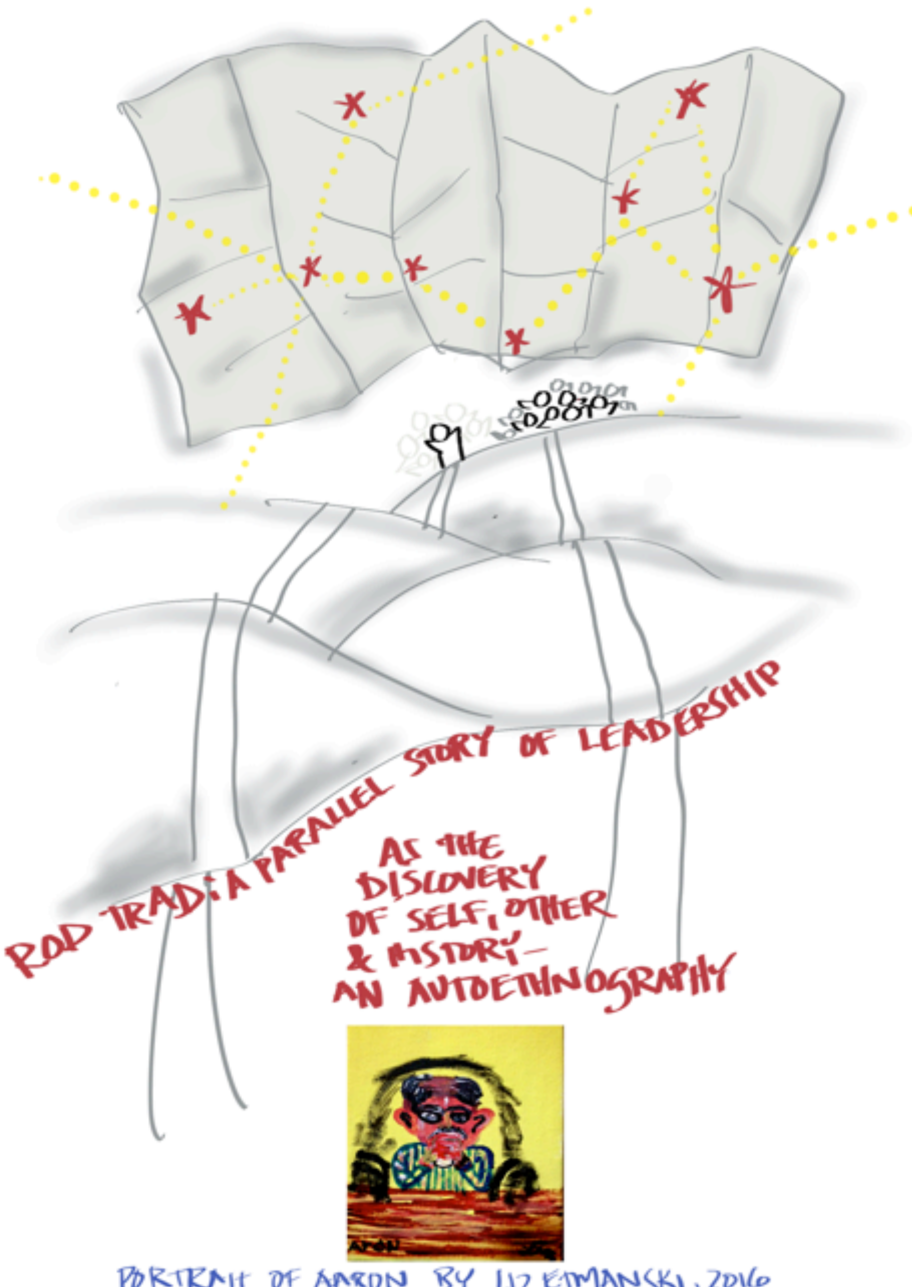


Figure 31. Graphic of Chapter 6, including portrait of Aaron Johannes by co-researcher Liz Etmanski.

Abstract

Autoethnography is a qualitative research method that allows us to draw on and explicate our own experiences of what we research in highly personalized ways that lead to increased understanding of the social problem we examine, through a different

research lens. While in other research methodologies we dance around pronouns and our researcher's stance: first person or third person or formal anonymity – in autoethnography not only are we in the room attending to the action, we are documenting our own responses and transformation. Autoethnography is part of an ongoing debate about reflexivity and voice in social research. In this case, as I came to the end of my research I wrestled with what had come to seem to me to be the preciousness of my own absence in the other parts of this dissertation. In fact, as my advisors said, "We trusted you." When I talked to them about this issue of pronouns and subjectivity they said, "Well of course you are here – that's the point!" As Price and Kerschbaum (2016) have written "disability crips methodology" (Abstract section, para. 1). This research only happens within two decades of relationships, within grief for our common losses of common friends, and shared puzzlement about why things are the way they are. How did I get access? How do you not have access? In this autoethnography, I attempt to delve into my own experience of being othered and of being loved/loving the othered and being transformed by my experience of them. This thinking leads me back far beyond the beginning of any academic interest and into a childhood in which difference was indomitably refused and the ideology of belonging was handed like a torch to the next generation by people who did not recognize their actions as political and would have refused to call themselves activists or even advocates.

Relationship of this Article to the Dissertation

In researching the question of this dissertation: for people with ID, what works to support them in leadership in their lives, groups and communities? It becomes apparent that the idea of any single discipline lens does not serve either people with ID or those who care about them and their potential input. Further, to focus on being welcomed in, rather than observing from a unaffected distance as in traditional research, may leave both researcher, the researched subject and the reader incomplete:

> *Ellis (1991), a strong advocate emotion-based, autobiographical inquiry, has suggested that a social scientist who has lived through an experience and has*

> *consuming, unanswered questions about it can use introspection as a data source and, following accepted practices of field research, study him- or herself as with any "n" of 1. "Experimental writing means re-thinking the condition of representation and therefore [engaging] with figures of subjectivity that do not depend on representation as it has been understood" (Clough, 2000, p. 286).* (Wall, 2006, p. 148)

In fact, oppression has been the focus of single disciplines such as Education, without a sense of what happens to people with ID as adults, or behaviourism, coming out of a corner of Psychology, without a sense of what exists beyond the medical model. Increasingly, we know that we cannot separate out any aspect of health as if it exists alone.

> *Disciplinary specialization was at natural result of the increasingly systemic study of the world, with the development of the universities, and attempts at organizing knowledge. The organization of knowledge in academic departments reflected the Cartesian/Newtonian worldview, which saw the world as being made up of closed, mostly noncommunicating parts. in order to understand these parts one had to dig deeper and deeper inside the part. Maintaining clarity and coherence required a strict Aristotelian logic: something was either A or B, but could not be both A *and* B. The organization of knowledge separated disciplines into "clear and distinct" spaces, increasingly smaller demarcation from everything around them.* (Montuori, 2017, p. x)

Our physical health, our heartbeats, our neural pathways, our very skin, respond to our social connections (or isolation) in ways that we can now monitor and assess (Cacioppo & Patrick, 2008). Emergent research in both leadership (Hersted & Gergen, 2013; Hornstrup, Loehr-Petersen, Madsen, Johansen, & Jensen, 2012; Uhl-Bien & Ospina, 2012) and research methodologies (Roets & Braidotti, 2012; Britton, 1996; McNamee, 2014) demonstrate that a relational focus, that does not deny that our processes are relational, is beneficial: "a politics of affirmation" (Roets & Braidotti, 2012, p. 161).

It is unimaginable to me to settle for a mere formal thanks in the acknowledgements of this dissertation that does not reflect the profound changes to my own character, thinking and social networks that has occurred within this research. Part of what happened here was that I spent time with a research question; the most important part, for me, was that I got to experience what it was like to call for help

repeatedly over 3 years and have a small group of people respond with jokes, cards, phone calls, drawings on napkins. The research question was also important to them, perhaps even more important as they were grateful to be asked what mattered to them, but the goals never superseded for a moment their profound care for me. This chapter attempts to encapsulate some of the thinking and feeling that occurred within the research paradigms used in this dissertation through the form of an autoethnography (Wall, 2006). As Bochner and Ellis (2016) document in their work with so many researchers, "I can't see doing this project without including my own experiences" (p. 17). I am reminded of time spent with one of the early researchers in our field who had written a work that was seminal to me. I was thrilled to meet him. He had moved on to other fields, still traumatized by some of what he had experienced at he hands of a system that he had entered into with the belief that everyone had good intentions. He shrugged. He had only come to the event because a mutual friend, a person with a label, had asked him to. It was the relationship that compelled him. Then he told me stories of conversations and meetings and relationships that he had been involved in 30 years before. He was happy to connect with some of those people, happy to meet new friends but the whole part of his life that had to do with the research was encapsulated and walled off and he wanted little to do with it.

People with ID, as long as I have known them (and in this section of the dissertation it will become apparent that even though I did not know it, I knew them all m life), have seen leadership as a meaningful issue in their lives, groups and communities. In the conversations I have had, from the beginning of my career as a self-advocate supporter and volunteer, and throughout the conversations related to this research, they have wanted more clarity and from the beginning they saw this as necessarily co-created. This frustration with rigid roles is also reflected in the research (Goble, 1999). They welcomed the idea of an exploration of what leadership was for them, and how it might differ from traditional expectations, so that they could leverage their capacity in different contexts. In practice this section of the dissertation answers the more practical aspects of this overall research, perhaps as another side of the

questions addressed in Chapter 3, by demonstrating what methods might involve researchers with people with ID, by documenting one's own transformation in the relationship with them.

"A Conversation has Other Laws"

And each

speaker of the so-called common language feels

the ice-floe split, the drift apart. (Rich, n.d., Stanza 1, para. 1–2)

What I learned about leadership from people with disabilities after 3 years of research: the first act of leadership is to tell your story. The second act is to notice who leans forward into the story. The third act is to grow the stories together.

To tell your story, even more than becoming articulate, requires someone listening to you. It requires an assumption of reciprocity, acknowledging that the distance between one and the "other" might not be so distant. In fact there may be no distance.

It requires honoring the idea of a story as itself – not as a tool, not a weapon, not data, not proof of anything, but as its own thing. When my Belgian advisors said, watch for the *röd tråd* – the "red thread" that holds it all together and makes something contiguous . . . the *röd tråd* of leadership and intellectual disability is the idea of story.

On the etymology and language usage site, StackExchange, an anonymous user named ihatetoregister, wonders whether the idea of "red thread" means a theme, in English. Someone responds that in Sweden, "*röd tråd*" (literally "red thread") is used to describe that something follows a theme. For instance, if a piece of text has a "red thread," it's written with a consistent thought throughout the text." They suggest that it comes from the story of Theseus who found his way out of the Minotaur's labyrinth by following a "red thread." Or, they suggest, it might have something to do with a symbology of cordage as it is used in the English Navy. The cord tells a story and everyone with the same cords is part of the same story. Someone else says that the Russian navy took this expression from the English Navy's cordage, but doesn't explicate this. You could only "hear" this story if you knew what to look for.

Perhaps, asks another, it is like the English word, "leitmotif"? Someone else says that while it is close in imagery to "red tape" it has a completely different meaning. Ariadne's thread? someone suggests. Breadcrumbs? They return later to say that they

only meant in the sense of something out of myth or story that had connotations of creating a path to follow. It is like, another suggests, the red thread of destiny tied by Chinese gods to those who are to meet and help each other in certain ways. It is certainly not like "red tape." A Sherlock Holmes fan remembers that he once remarked to Dr Watson: 'There's the scarlet thread of murder running through the colourless skein of life." Someone careful and definitive pops in to say that it does not equate to anything like the idea of a breadcrumb that creates a trail to follow because it has unique connotations that refer to "consistency and 'togetherness' (or lack thereof)" (Jacquet, 2013, para. 31) in a narrative.

I like reading these careful voices so concerned with the articulation of the denotation and connotation of rare foreign words. They are, themselves, creating a "*röd tråd*" as they pursue meaning, images in the gaps of their conversations.

I am showing my data to my friends with disabilities, demonstrating how by using grounded theory methodology the themes of the community conversations come together, and showing them the hyper-scribe program I could use to sort out meaning-units even more scientifically if I chose to, putting them together, weighting emphasis and number of metaphor, to find out what's most frequent and most important. Look at my graphs!

"But this isn't what we wanted," Gordon says. Barb shakes her head sadly, "No, it's not." "We told you our stories – you have been with us for so long and we have all told you our stories and we trusted you with our stories. That was your research. It's not data, it's stories." Liz also shakes her head sadly, "Of course."

Plain language, they said. We are left out by your language, this is the first exclusion for us. We can't even respond. The tower of Babel is not a place we need to travel to, it's what you make for us.

How long have they been saying it? Listen to our stories. The very first project of People First of Canada was oral histories: *Our Stories: The Stories of Some of the Leaders of People First in Canada and A workbook for People First Member To Tell Their Own Stories* (People First of Canada, 1993). Did their stories grow the idea of People First and

make it manifest or did People First create the fertile ground and notice the gap that needed filling. Even in this, it was not about the storytellers but about the potential for others to tell their stories too. The collection of stories begins:

> *History books are usually about important people and events which really made a difference. This is a history book.*
>
> *People First members are important people. They do things that really make a difference. The history of People First members and groups is important.*
>
> *We think it is important for People First member to tell their stories. When we tell other people our stories, we tell them our history. We tell them about important things that have happened.*
>
> *When People First members tell each other their stories, we learn what we have gone through. We learn about the hard times and the good times. We hear about things that happen to people who have been labelled. We find out what we have in common. We find out all the different things that can happen.*
>
> *When you tell other People First members your story, they learn what your life has been like. They can learn from you. And when other People First members tell you their story, you can learn from them.*
>
> *Our stories help us find out how things can be different. You hear about how other people have dealt with issues just like your issues.*
>
> *When you tell other people your story, they learn what life is like for you. They hear about things we can do. They begin to think differently.* (People First of Canada, 1993, p. 1)

There are, say the authors, some common things People First members might want to tell stories about, and some easy ways to collect stories:

> *It was pretty easy to get the stories. A friend of ours had a tape recorder. He sat down with each person and asked them some questions. They just had a conversation. Then someone listened to the tape and typed it up.* (People First of Canada, 1993, p. 2)
>
> *The next section is about what to do with the stories: "Read the Stories, Think About Them, and Talk About Them," "Tell Your Story" (individually or as a People First group) or "Practice Telling Other People the Stories You Have Heard." The last line of this section reads, "Then, you can introduce the person who told you his or her story to the rest of the group."*

This story project was lost for years and only found in an archive. Yet, repeatedly, through this research, people followed these ideas and instructions, as if resonating with this historic conversation.

It is easier and more expedient to listen to the stories we want to hear. Structured in certain ways, told within certain limits, and using a language that is comfortably distancing.

That's privilege. We respond with words that make things matter more or less. Privilege.

"The Loneliness of the Liar"

The loneliness of the liar

living in the formal network of the lie. (Rich, n.d., Stanza 2, para. 4-5)

All or almost all of us have told a lie at some point, and then walked with the weight of having to remember what we said, and what lies we then used to build on that first untruth, what shaky supports?

One of the truths that arose in this research was that we don't need to leave anyone behind. What happens if this is our shared assumption, that we will all form a circle and move forward together. If the "to go forward" in the etymology of leadership as a word assumptively means, go forward in a circle. Leading in a circle. We don't move forward alone. Ever. Everyone belongs in the circle.

On the other side of this, the lie of not belonging. Of the creation of instruments to distance and damage, to expedite and categorize. We just need to remember what lies were told to prop it all up, to keep the shaky structure standing.

"Silence Not Absence"

Silence can be a plan

rigorously executed. (Rich, n.d., Stanza 3, para. 4)

Learning To Speak from the Inarticulate

In the bible town children should be seen not heard and what was heard anyway

Was the artifice of a T.V. world so when my aunt handed me the potatoes
And said ask your uncle does he want some, and I said he has passed out drunk
I got smacked he is not drunk he is not passed out he wants potatoes don't you
Uncle? and my bleary dad roused himself enough to say damned kids . . . sure I'll
Have some potatoes for Christ's sake

It was like that

There was a girl where I was born lets call her Rachel born when I was born
but with Down Syndrome and in the maternity ward her mother and my mother
side by side and when the social worker came to talk about institutions
Her mother said no, you are not needed, we'll be fine and my mother said, too,
We'll be fine (Oh I was so mad I couldn't believe it Just imagine) and was a good friend
for a time perhaps because she, too, had lived
With someone no one else could understand the only person in our bigger family
Who read the books I loved and could talk about them but no one could understand

Really? I could understand him. His family understood him
Anyone who spent time with him understood him
He knew history and stories and politics
He had ideas
He was the smartest person I knew

    Too smart for his own good, my grandfather used to say

And when the priest came and said this is what happens when you marry
A Protestant we warned you my grandparents returned to the Catholic church
Doing penance every week but said we'll be fine

    It might be easier if he was not so smart, they used to say
    Because he can understand everything

Rachel was sent to a different school my mother didn't see it as politics
To offer to bake 200 cupcakes if our school would let their school come
to our sports day

They said no

At 30 I am talking to recreation therapy students about disability and sports
Inclusion and access and potentiality and belonging I look up at the screen
The photo of someone in a wheelchair playing basketball
I am stopped with surprise
I call my mother when I get home to say my uncle has a disability
What a horrible thing to say she says, who ever told you that
My mild mother is furious. Much later I will learn that for her this sentence
"He has a disability" or some variation had always ended with "and
he doesn't belong here" where she was taking him (the school the store the church
the skating rink the bowling alley the kids' club)

He is not disabled like the people you think of as disabled, she says
And anyway it doesn't matter
Her final word

At 35 I am talking to a mixed group of people in my bible hometown that

> I never go to because I was made speechless there who are you dating
> A sailor a film producer a poet a pedophile beer bottles sail out of cars
> Aimed at my head and I have to take to the alleys but that, too, is
> Dangerous I am threatened everywhere the soccer team comes to the pizza
> restaurant where I work
> And waits for it to close to beat me up my boss gives me a ride home and fires
> Me as we arrive at my house the only lesbian I know tells cruel untrue

stories about me to accrue points with the ones who hate us

my grandparents tell me my uncle has a new job, he likes it, he has
always wanted to work later, he arrives home, his clothes in his carpet bag
they say it didn't work out but, well, he'll find another job
he says to me they put me in a home with ten other guys
they sent me to this workshop where I had to put things into packages
and talked down to me no one else could talk I was reading
history I was reading about the Golden Spike and I tried to talk to the staff
and they said we aren't here to talk to you
you need to go over there with your kind, so I threw
the book at them as they say

threw the thing he loved more than anything
split the spine
got kicked out of the program
damage and damage

there are no services the social worker said you made a choice here to
keep him home there is a perfectly good institution they train
them to work he could have had therapy he could have been
with his own kind I don't know what he's saying it doesn't matter anyway
My uncle buys a studded black leather jacket he chain-smokes oils his hair
he hangs out at the pool hall he drinks beer he becomes the only possible
version of himself Like James Dean but hobbling, his leg dragging
behind, his voice stuttering, slurring, inarticulate
to those who do not love him

I am dating a sailor, he's really interesting he's been everywhere

He’s done everything he’s seen the pyramids he’s been to Tokyo
He knows so many languages and mostly he knows how to swear
And he explains to me about art and composition and photography
and gives me books no one has read and
Somewhere there are photos of me, nude, black and white,
fifteen years old
The boy who had been nowhere

If you tell me this again, my mild mother says, I will have to disown you
If you were a murderer I would visit you in jail
But if you are this, I am done with you

Be silence
He introduces me to beer and wine and port and whisky
To grass and mushrooms and complex chemical combinations
And how to build a fire how to tie knots
In the dark room, red-lit, we are safe
We are natural

Until the door opens

We meet in secret; in public we are pals
I am his entry into the bible town

I need to be with a woman I’m not sure what I’m doing here but
It’s been fun thanks I introduce him to my beautiful friend and they date
I don’t understand she says later he only wants to talk about you
I finally said to him oh shut up about him
Like a pimp I introduce him to another friend

What is with him he only wants to talk about you I said to him
If you would rather be with him go out with him and
He started yelling at me like a crazy person I'm not seeing him again

I can barely raise my head to acknowledge her I am on my own only
Path only possibility I have dropped out of school where the whispers
Follow me from class to class the secrets weighing me down the
Narrowing vision of an impossible future
Jump off a bridge?
Pills?
Razors to the wrists?
Jump in front of a truck?
Oh wait I will drink and drink and take drugs and not eat or sleep it'll be fine a long
Petrification the best I can hope for

Unlike my friend Dougie who would call himself Della and dance
Into the path of an oncoming bus
Unlike my friend Roland who would hang himself by his belt
Unlike Keith who would say at 40 well no one will want me now
And shoot himself
Not like Linda who could take a car apart and put it back together again
And one day on a whim built my mother new stairs to replace the rotten ones
And my mother said she certainly is masculine is there something wrong
With her and Linda drove into a tree
She was a fast fast driver
It's a long long list
And then AIDS
A longer list

So in the sheltered workshop in the bible town
A small group of women with Down Syndrome cluster and I remember
Rachel let's call her Rachel because I don't really remember
And I call my mom remember the girl with Down Syndrome I was born with
And you stood by her mother and once there was a sports day and
You said why is she in a special school and they said they are all in the special school
And you said why is that could they not come to ours?
No I don't remember that at all, she says
I'm sure I didn't do that
Remember you made 200 cupcakes and hot dog buns and you said look we have
All these cupcakes and all these hot dog buns and they might as well come
And they said no no no

Oh I remember the 200 cupcakes good lord why did I make those?

You believed we all belonged but
Not even I belonged in that school
Not even a divorced woman you
And these days, so many days later, so many years
I am married and have children and we live in a house respectable
In the big city we are the gay neighbours the nice boys helping
The elderly woman next door, the perfect family across the street
Doesn't want anything to do with us they're godly they want
To be nicer than us and more included but aren't
but otherwise
Here we are
An impossible future you would never have imagined
And I never dreamed of

At their big conference when I ask what people with disabilities are proud of
They say we have our own books now
The books are unimaginably hard won. To read and write is hard won and
They depend on helpers sometimes the helpers are the same
People who are the oppressors but they're really really nice
Nice oppressors nice nice the patience of Job
In your next life you will be rewarded

Not all the books their names are on are theirs
What do you like about your life? Here let me get you started you like
This and this and that and this. . . .
Let me help you finish this you are happy
Here is your book
And my friends say I only knew the outsides of the buildings in the town
I was not invited in I only got to go places that were called community
When the staff chose to go there was when no one else was there
And they called it community inclusion
It meant going to the mall

Well that's not a very nice story to tell is it?

The up north community inclusion program
staff said that nothing I talked about would work
For "their" people "they" won't be included anywhere "they're" too
Hard and "they" don't talk even so from the podium I said hey I'm not
Doing anything tonight can I meet them?

They don't talk, they said

It’s okay, I said

They’re not the people you’re thinking of, they said

It’s okay

Breaking the fourth wall in this performance of us and “them”

They shift in their seats

They said um sure um okay ahhhh in an hour we need an hour

What they needed the hour to do was all of them go home and

get their uniforms and change

Because they could not be in their workplace without uniforms

Their workplace – “their” home

Which rules? On the door there is a sign says

This is a home it is a home like any home

Please knock before you enter because

These are people who live here

When they open the door there is a sign says

Please take off your shoes employees must wash hands have

You had your flu shot employee bulletin bowel movement charting sheet

In the living room a sign saying staff must take care of themselves

Here’s how to lift someone here’s how to give meds

All the staff are wearing uniforms and name tags now

Why do our people have so much trouble fitting in, they wail

We care about them so much but everyone stays away

Where to start . . .

In the mixed group in the bible town where I have been speechless

I am now a voice invited in tell us about relationships
Tell us about how to teach inclusion tell us about how to connect
Tell us about community development tell us
Perform for us (then go away)

Is it her? Is it Rachel?
What did I miss is what I wonder
How long this path has been how many silences how many hesitations
What about if it had been different if she was still my friend my friend
The whole way through our lives in that class where the teacher had me stand
At the front on the room visible to all to point out the flaws in my math
That room where no one wanted me to sit the other grade threes think
You're ridiculous you do not know your times tables hahahahahaha
What if we were friends the way
We were friends swinging on swings teetering on teeter totters would
She have held my hand would she have said I was okay I was whole I was
Going to live through this? In this room the woman who might be Rachel
And her two friends are having so much fun they love the workshop
Let's not talk about what's missing let's talk about the gifts we bring
Let's talk about who we love who loves us

They nod and nod yes and yes hahahahaha

The manager of the program comes up on the break: is this useful?

At the end of the day one of them comes up to me, shy, uncertain
She hands me a piece of paper and her friends, touching her, encouraging
Her, grin and nod more yes and yes
I open it up and there's me, a roughly drawn sketch of me listening

Surrounded by others who are smiling and telling stories
They all have hearts shining
In their chests and they are connected holding hands that's not what we
Did but it is what we did
Is this Rachel? Does it matter?

This is part of what makes us possibly complete

In the first job, with my shiny new teaching degree, averse to schools
I discovered people with disabilities supported by an industry I knew nothing about
It was a surprise to me they were in the back yards that joined our back yards
All the time it was a surprise to me that there was an industry
The big big room the many folks gathered, the staff on one side making
Communication programs, inarticulate people on the other side, being . . .
Inarticulate. I drew pictures of coffee cups and toilets and when people pointed
To the coffee cup I took them for coffee. No one ever pointed to the toilet.
I got written up for subversion.
Each of the 30 people who could not talk would one day benefit from their new
Communication program which would only be complete once we had
300 pic-syms for each person, each one plasticized, velcroed
in labeled boxes organized by themes the ways I feel the places I go the people
I know what I like to eat what I need to do. They would, then, be
ready to go. Ready for life. Ready for access. Ready to talk.
When we were done making these pic-syms. Snip snip snip glue plasticize
Stick the Velcro on the back.
It had been 27 months since the 10 days of training that made the staff
Professional. My teaching degree was nothing. Paulo Friere Paulo Who?
Was nothing. Questioning the idea of tabula rasa assumptions: nothing.
They had this special 10-day training. Certificates. Only on Fridays

Were people free of creating the future communication programs.
On Fridays the staff who liked to cook gourmet foods would have us line
Up the wheelchairs and we would also take places make a theatre and he would
Cook and demonstrate to us like in a cooking show how to make fancy
French dishes. When I made a sign for Fridays that said "Observing the
Julia Child Cooking Show" I got written up again.

When one day Vicky grabbed a picture of a coffee cup, showed it to me, and headed
Towards the door they said I couldn't go and disconnected the gears
on her electric wheelchair
She never should have been considered an appropriate person for this program
Anyway. She doesn't even want to learn how to communicate she screamed
I can talk damn it but they had this 10 days of training so they knew these things.
And she has a behaviour problem but no behaviour program so we don't even
Know what do with her. I had a degree
In the history of the literature of marginalized people, the sociology of education
What did I know? We were all learning our places.

Unless we weren't. Vicky sobbed. Made inarticulate and immobile. I left.

Later, I would find Arnold, head of a group of people who wanted to speak
For themselves. It isn't easy Arnold said. Once Gerry stopped a conference
To listen to someone no one could understand because he said
our job is to listen to everyone, until we understand. She spoke on and on –
listened to, the magic of being heard, speaking like a river, burbling
All the people with disabilities in the room, leaned forward, listening, hearing
When she was done she said, clearly, Thank You.
Those of us who did not have disabilities were I dunno maybe embarrassed. Afterwards,
Lorie said she's going to be a great leader one day

and we were there when she first spoke up. Mark it down, she said.
You know how to write. You know how to make a mark. You have pencils.
All around the room, people with disabilities make an X.

And the next year, when she again got up to speak, I thought oh no but
The thing is, I could understand her
They were right I was wrong
And she was calling for a world in which we were human
With each other. She had been raised with another woman since they were 3
She was "like a sister."
And now separated and put into different homes because
There was an assessment and one of them had higher needs than the other
One of them had a higher IQ so was expected to be
More independent
So her friend had to go to a less costly home with less supports
Instead of staying with her, the one person "like a sister" the one person
"like family" the one she depended on
is too smart for me?

She has a problem but no program we don't even know what to do with her:
Be human

Arnold was in trouble with the feds. His group had got a grant; they had done
The work but no one knew how to write the report. They didn't trust anyone
To write their report. It was our work, these are our stories we don't want
to give it away who knows what you will do with our stories?
But they needed more money and the feds called him
To Ottawa for some explaining. I was sent with him. I worked hard to prepare
Stacks of reports and spreadsheets and goal statements and milestones and

Interviewed people and gathered old receipts I know what you want I can walk
Two worlds or more and when we were ready we left
And when we got there as we went into the room oak paneled with a big desk angry
Bureaucrat I was left holding the bag for your silence he said and Arnold said to me
In a whisper let me handle this I know how it's a hot seat. Explain yourself said the
Government man. Let me tell you a story, it is a story everyone wants to hear
Arnold said. I was born with a cleft palate and a clubfoot and in those days they
Called it excuse me for saying this but I must because this is what they called me
In those days retarded they said to my mother she was a single mom and in those
Days that wasn't good will you be able to pay for his braces will you be able to pay
For his operation? Who will take care of him when you are at work? He will need
So much care he will need care all the time are you a Doctor are you a Nurse
and she was just a single mom in a world where that meant she was bad
She couldn't so she said yes and they said it will be better if you forget him if you
Move on if you try to change your life and be good
And they put me into what they called an institution and I called it a hellhole and
Then I went to foster homes and everywhere I went people saw what I couldn't do
And I showed them I learned to read on my own and I have a computer and I wrote
A book and I told my story and I found my mother and my family after 40 years
Of searching . . .

At the end of the meeting they gave us more money, they didn't want to see
the reports and the government guy leaned over and said to me, thank you, thank
you so much I have never seen such good support to someone before
Ottawa needs you, our country needs more people like you; we need to hear
These stories. I had said nothing. Call me if you want a job he said.

There is so much we don't know, he said. Thank you.

He was saying, we are incomplete. I feel it too even behind this big desk
We are not whole without
Everyone's voice.

Inarticulate is unheard

- impatient not-enough-time not-my-job somewhere-a-professional-does-that they-can't-talk

and Gerry says, it is our job to listen until we can hear what they are saying

Arnold wrote a book. Arnold's was the first
I'd heard of. It was the idea of a book. By someone who mostly taught themselves
To read somehow not much was expected of maybe some rote learning maybe
Some training – someone trainable not uneducable not educable in that old
Taxonomy . . . autocorrect changes it to that only taxonomy and I change it back
But that's right too: uneducable trainable educable

Someone finds out that I was Arnold's protégé and tells me a story
You will want to hear this story you think you've heard it all but this
Is a story everyone wants to hear
There was a workshop about theatre of the oppressed and Arnold took on
The role of social worker. He was bitter and deterministic and controlling
He vetoed things and confused everyone on purpose and blamed others
And when it was time to come out of character he wouldn't he was strident
With big words no one knew he knew and a meanness that was unexpected
They say to me, I understood watching him what we have done to people

He was articulate and professional

Arnold was not sure how books get published he didn't care

He learned how to use a printer just as he'd learned how to use a computer

I taught myself to read and writer Aaron I can do it all

The copies were gifts to people who had been, in his mind, real allies

I can cover the walls of my office with papers like wallpaper

but one of the things I am most proud of

Is that I got three copies of Arnold's book. But each copy is different. The

Story changes. In the last version that I received, it is not about self-advocacy and being

a leader and part of a movement. It begins:

Arnold Bennington's Story about Being Reunited with his Family

> *I'm going to start from the beginning. In the year 1949, I was born with club foot. And then my mom did not want to give me up from birth. It was decided. . . .*
>
> *. . . they had told her to forget me and she said fifty-two years later oh*
>
> *I never did forget you how could I*
>
> *The end*

When I am asked to do a workshop for the community centre who want

To be welcoming to diversity so can I come speak to them about that and

People with disabilities how might they be welcomed too? I go and the room is

Full of bright young faces, earnest, ready, their pens poised over their notebooks.

Tell us about disability tell us about belonging tell us how to be welcoming.

What is wrong here, all these years later

Oh I could never forget you and I never did

How could I? And I shut down the PowerPoint and say who here knows someone

with a disability? Who has a brother, sister, nephew, niece, uncle, aunt or child

with a disability? They raise their hands one by one. Who has a neighbour? A co-worker

and if you said no to co-worker why not? Who goes to a Starbucks where

the guy with the disability greets you and makes your day? Everyone has their hands up

now. Tell me, I ask, about the person with the disability.

What do you know? What do you feel?
And they tell me stories. We tell each other stories.

It becomes a way to begin for me. Afterwards people come up and thank me
Thanks for allowing me to claim this person I didn't know how.
Sometimes it is their sister or brother and they were lost. Between the lines
They tell me, I was lost too. I am found in this new story of welcoming.

One day someone comes up, angry. "You did not say great-aunt!
I was waiting for you to say great-aunt – I wanted to claim my great-aunt whom
I adore. My favourite person when I was a child the only one who cared.
She bought me a budgie in a cage when no one wanted me to have a pet it was
Too messy. *Where was she?*" Exactly. Be angry. Please.

Let me tell you a story. It is a story that everyone wants to hear.

It is the story of all of us, incomplete until we come together, completed.

"Can I Break Through this Film of the Abstract"

> *Can I break through this film of the abstract*
>
> *without wounding myself or you*
>
> *there is enough pain here.* (Rich, n.d., Stanza 4, para. 2–3)

My mother living in the small town was sad all her children were too far away to make cinnamon buns for; they got stale before they could be eaten; what would she do with her life? Who was she with no one to bake for?

When she saw the two people from the group home walking out of town she called the man who ran the organization and he said they do that, they keep trying to

escape, it worries us. Thank you for calling and if you see them do this again tell them to go home.

The next time they walked past, resolved in their desire to find some better world, my mom came to her porch and called out, “I am making some cinnamon buns – do you want some?”

“Sure!” they said. “We’d love some!”

After that, whenever they wanted to run away, they would come for cinnamon buns at my mom’s house. “I guess you’re not the only consultant in our family!” she said.

“If There were a Poetry Where this Could Happen”

If there were a poetry where this could happen

not as blank spaces or as words. (Rich, n.d., Stanza 5, para. 3)

The first thing that my advisory group of people with disabilities told me was that leadership for them was going to look different from how I might think of it. If you look for the leaders you’re expecting, at the front of the room, it’ll just look like we’ve failed again. Our leadership happens in our lives, our groups, our communities. Sometimes it happens at the front of the room at the podium, but sometimes it is just about us choosing when we’ll go to bed and what we’ll have for dinner. They looked it up in the dictionary: “leader.” There we are, they said.

Figure 32. A first step in collaboration was to look up 'leader' in the dictionary.

At the very end of our research, at the end of the last meeting, Barb said, in frustration, "Who invented this thing called leadership? Whose idea was it? I thought we were all in this together." They are words that turn Darwin's meritocratic world on its head. Does the idea of leadership itself, as it assumed to have different qualities than the norm, just distance and other some of us? What does this question mean to a population so alert to being differentiated?

We might think here of Derrida's (as cited in Reynolds, n.d.) idea of hospitality as signifying that someone is the master, and hence in control, and thus has the power to host. In hosting, identities and empowerments are established, as if the guests were not controlled in the ways they are welcomed in, they are no longer hosted, they have taken control of the space (place, organization or country).

> *[Thus,] any attempt to behave hospitably is also always partly betrothed to the keeping of guests under control, to the closing of boundaries . . . in which our most well-intentioned conceptions of hospitality render the "other others" as strangers and refugees.* (Reynolds, n.d., Hospitality section, para. 2)

Arnold Again

If Arnold was not "retarded" – I'm sorry, I had to say that word, that's the word he used. A word with power, taken back by those who had been most hurt by it. Not like "nigger" used in a rap song to subvert and claim, but repeated back to those who in their earlier incarnations used it without considerations: is this still what you believe? I could never hear the word "retarded" again without hearing his voice speaking it, in dramatic disbelief. I know, I know, he'd mutter, it's hard to believe. And it was.

And if "retarded" isn't true – and obviously it was not – what does that mean to the rest of reality? What else isn't true? What have I been told about myself that is not true? What have I been told about us that is not true? I turn again and again to this passage:

> *My hope is to demonstrate that virtually all intelligible action is born, sustained, and/or extinguished within the ongoing process of relationship. From this standpoint there is no isolated self or fully private experience. Rather, we exist in a world of co-constitution. We are always already emerging from relationship;*

> *we cannot step out of relationship; even in our most private moments we are never alone.* (Gergen, 2009, p. xv)

The act of caring for and about someone who has been labeled and is moving towards emancipation is a continuously radicalising act, “always already emerging” (Gergen, 2009, p. xv).

“This was the Silence I Wanted to Break in You”

> *The scream*
>
> *of an illegitimate voice.* (Rich, n.d.), Stanza 6, para. 1)

Goffman (1896) states,

> *Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories. Social settings establish the categories of persons likely to be encountered there. The routines of social intercourse in established settings allow us to deal with anticipated others without special attention or thought.* (p. 2)

Where people with ID are members of social circles of caring others, they are also “anticipated others,” but in other social setting they are (a) not “encountered there,” (b) not anticipated, and (c) there are no predictable routine social intercourses that do not require “special attention or thought.” So, the assumption of inclusion is that we are prepared in some way. The lack of discussion, given that there’s no need to discuss what we are prepared for, creates Titchkosky’s (2011) conditions for an “excludable type by signifying it as an always-absent-presence” (p. 90). Or, for what Goffman (1986) calls a phantom acceptance:

> *The general formula is apparent. The stigmatized individual is asked to act so as to imply neither that his burden is heavy nor that bearing it has made him different from us; at the same time he must keep himself at that remove from us which ensures our painlessly being able to confirm this belief about him. Put differently, he is advised to reciprocate naturally with an acceptance of himself and us, an acceptance of him that we have not quite extended him in the first place. A phantom acceptance is thus allowed to provide the base for a phantom normalcy. So deeply, then, must he be caught up in the attitude to the self that is defined as normal in our society, so thoroughly must he be a part of this definition, that he can perform this self in a faultless manner to an edgy audience that is half-watching him in terms of another show. He can even be led to join*

> *with normals in suggesting to the discontented among his own that the slights they sense are imagined slights—which of course is likely at times, because at many social boundaries the markers are designed to be so faint as to allow everyone to proceed as though fully accepted, and this means that it will be realistic to be oriented to minimal signs perhaps not meant.* (p. 122)

Dreams

Here is the moment I changed. Barb Goode wanted me to draw for a workshop she wanted to have for people with disabilities at a conference. Her theme was the Sound of Music, a favourite movie for people with disabilities (not to make an assumption, but having had to watch this movie, which I don't particularly like, so many dozens if not hundreds of time I feel I am allowed to state this), and the workshop was called "Climb Every Mountain."

More than 100 people with ID came at 8 a.m., hungry for belonging.

The workshop began: How many of you feel you have been put on this earth for a higher purpose? They looked at each other in puzzlement: who asks this question? What kind of a question is this? Is this a good question? Is there an embedded trap in this question?

(Let us stop the action and imagine it – this was a new question they had never been asked before: Were you put on this earth for a higher purpose? Imagine how your life changes if this is an unasked, unimagined questions?)

One person put up his hand, and then another and then another, and finally the whole room was full of the waving hands of people claiming their higher purpose, their faces shining with a new idea, a new self concept. Barb nodded.

"Put down your hands, please. Now, think of what you do during your days. Do you feel that what you are doing is working towards the higher purpose you have? If you do, put up your hand again."

People, again, looked at each other. Some hands started to crest, and then came down, other hands wavered, and then were still. A few hands went up, proudly. Barb nodded. "And this will be the subject of our workshop: what mountains do we want to climb, who needs to know about them and how will we get there."

My friend Shelley said, “We cannot un-see this.” Everything ever since, comes out of this moment, of hands raised and reaching for their dreams and purpose and then wavering, falling, unallied with their purpose.[3]

Poverty

I went to a workshop on poverty and disability. There was a panel of people with intellectual disabilities and I knew many of them. They told their stories. One, a powerful woman I knew, told a story about going for pizza one night with friends from work. “I would always wish they invited me along,” she said, “and then they did.”

They had beers and then, what the heck, two more.

Afterwards she could not quite pay her rent, so she had to ask her parents, who mentioned it to her social worker and they all wanted her to understand this was a natural consequence she would have to deal with on her own.

It signified her incapacity to be self-determining and live alone. Her social worker came to investigate whether she had enough to eat, walking in and looking in her cupboards: tsk tsk tsk.

Her landlord said it’s not a big deal, just forget it if she needed to, but she said no, and took it out of her next cheque, which then meant she didn’t have enough money to pay for the bowling team that was been part of, so for the next season she sat at home and watched T.V. as there was nothing else to do.

“That’s a natural consequence,” her parents said to her. “Is it?” she asked us.

Folks who were innumerate talked about budgeting, but also having to be so aware of the possible repercussions of making a mistake, and how much anxiety this provoked. Running out of money led to conditions under which people could make judgements about your ability to manage the rest of your life.

In Britain some people with disabilities researched the mystery of how they were all okay, even though none of them got enough money each month to live on. Yet, they managed. They found out that it was because each month one of them would have

---

[3] When I tell this story Barb always points out that this workshop was created with her co-facilitator, Shelley Nessman.

some extra to share, and they would, without knowing that this was how it worked, take turns.

Part of their research was keeping track of their money. They had someone help them. The person said, “Why are so many of you buying children’s toys?” It was because so many of them had had one or more children taken away and put into care. They bought, without telling each other until that moment, toys each year of their children’s birthdays and put them away. One day, if their children came back, they would show them the toys and say, “You were never forgotten.”

Sometimes research is a poem.

Our leadership, they said, might look different than you expect. It might not be about who gets to stand at the podium at the front of the room.

“Till You, and I Who Long to Make This Thing”

It was an old theme even for me:

Language cannot do everything–. (Rich, n.d., Stanza 7, para. 1)

I am thinking about how shy I was when I met People First members. And then I am trying to count the role playing performances I’ve done with them. I can’t remember them all:

- Government fat cat, not listening to the mice
- Guy who wants a job and the social worker says its not realistic
- Guy who wants to have sex without a condom pressuring his girlfriend
- Social worker who turns on guy in a meeting after planning with him that he can move to his own place for a year
- Nun
- Person in an elevator
- A mayor
- A job interviewer
- Staff with a cell phone ignoring the person I am supporting
- Person being supported by a guy ignoring me and playing on his cell phone

- Mountain climber
- Guy moving through circles of relationships

And, today I drew in front of a group of people; tomorrow I draw in front of 100 people at a user experience of healthcare event and then I report back on their stories . . .

Arnold would be proud.

Once, someone read something I'd written about Arnold and sought me out. Actually this happened a lot.

He said, I want to tell you a story I cannot let go of, he said. Once, I brought in someone to teach a group of people with intellectual disabilities theatre of the oppressed. Arnold was there, and he was rubbing his hands, chortling: "I will be a social worker." He was the best social worker, I will never forget it – his voice, his intonation, his responses to people – you could feel the vulnerabilities, you could feel the defensiveness, the need for control . . . people started to move away from him, shield themselves from him, he followed them, enveloping them in his need to control.

And it just hurt too much. I did a thing I never do and intervened to tell him it was done, and he said, "What if you were like this and you couldn't stop?" I think of it all the time ever since, he said.

Parker Palmer writes that many who lack confidence in their voice and power, having grown up "in educational and religious institutions that treat us as members of an audience instead of actors in a drama," as adults are able to "find our voices, learn how to use them, and know the satisfaction that comes from contributing to positive change – if we have the support of a community."

He believes this requires the concurrent action of creating community, as "without a community, it is nearly impossible to exercise the 'power of one' in a manner that multiplies; it took a village to translate [Rosa] Park's act of personal integrity into social change" and that the "steady companionship of two or three kindred spirits can kindle the courage we need to speak and act as citizens" (45-6).

Arnold would ride his scooter through a room, weaving here and there, leaning across tables to laugh and tell a joke. “How do you catch a unique rabbit?” “U-nique up on it!” Whole tables of people leaning towards him, and as he moved on they sat up straighter in their wheelchairs, stood a little taller, or moved to a seat closer to the front of the room, believing in themselves and their ability to give voice a little more.

You think you’ve heard it all before, but this is a story everyone is glad to hear, Arnold would say to the powerful and controlling. Stories take us through when nothing else can. When there are budget cuts and someone at the coffer door holding us back from our dreams, a story can be a key to inspiring that person to travel with us, dream with us, be helpful, be an ally.

“From Which Time After Time the Truth Breaks Moist and Green”

for the return to the concrete and everlasting world

what in fact I keep choosing. (Rich, n.d., Stanza 8, para, 9)

I have always lived with people with disabilities.

I just didn’t know it.

When I was 33 I was giving a talk to a class of therapeutic recreation students about different ways to support people to be involved in sports and in different leisure groups in their community. blah blah blah. I looked up at the screen and there was a picture of a guy in a wheelchair playing soccer. I was struck silent for a moment, reeling a bit, thinking, “Oh my goodness – Uncle Jerry has a disability!”

Uncle Jerry was my favourite uncle in many ways. He read books. He had lots of time to discuss history and current events. He was the only one who ever said things like, “I think you would like this book about the history of confederation – the stories behind the scenes are very interesting if you think about the politics of the time and the politics now.”

Now I am not sure how to express to you how it sounded when he said that, but imagine that the words slurred together and some of the consonants were difficult for him to pronounce and as he spoke his whole face, including his lips and tongue, were

making tremors, the muscles shifting around in ways that had nothing to do with what he was saying, and his eyes rolled around a bit. And when he walked, half his body was dragged beside him by the other half, and one of his hands was like a claw.

He wore a black leather jacket like James Dean, the only one in the small prairie town he lived in to wear one, and he would put brylcream into his hair and brush it with his good hand and then shape it with his claw hand into a kind of swooping swelling arching curl at the front and a duck's tail at the back.

I called my mother that night, "Uncle Jerry has a disability!"

"What?" she said, "What a horrible thing to say – who told you that?"

"It's not horrible, it's just true."

"Well it's not. I think he has cerebral palsy. Well, something like that, I can't remember. It doesn't matter."

"How could we not talk about this?" At the time I was very concerned with planning for supports and service provision.

"Well it's not like a real disability."

"In what way is it not like a real disability?"

"Well it's not."

Things suddenly made sense. Some of my favourite stories of my mom's childhood had been about her adventures with her best friend Diane and Uncle Jerry, who was younger than her. "We went everywhere together. We were always together."

One of my favourites was about when they went skating on a very cold winter day – it was so hard for her to help him get dressed in layers and layers of clothing and then they walked all through the town, her and Diane each holding one of his hands to keep him upright, and then they got to the little frozen pond, and they realized that Uncle Jerry had wet his pants but didn't want to say anything because he wanted to go skating too.

"And of course the pee was frozen and his pants were frozen right through and he was crying but we told him not to worry, we'd still go skating, so we had to go all the way home with him and change his clothing and take off all those layers and then put on

more layers and then we had to walk all the way through the town and down to the little pond and everyone was leaving because it was getting so dark and so cold, but Diane and I put our skates on, and we put his skates on, and the three of us skating in circles and the sun went down and the moon came up and then your grandparents came in their car, shouting at us at first why hadn't we come home, and we said what happened and then they were okay with that, because he was obviously so happy . . . so they took us out for hot chocolate at the little restaurant and then we all fell asleep in the car and when I woke up the next day I was in my bed with Uncle Jerry and Diane and we agreed it was the best day of our lives."

Suddenly it all made sense.

To know someone with a disability well is a radicalizing act.

If it is not true that they are "other" and not true that they are "less than" – then what else is not true? What else is suspect? Who else is suspect?

My mother was not an academic or a very thoughtful learned person but she taught us to have, as she had, no tolerance for prejudice or assumptions based on perceived difference. Other parents helped their children with math, or read them serious literature, or helped them learn the piano, but as the son of my mother I knew my job was in any room where someone was different, or alone, to go stand by them and talk to them.

And yet, she didn't recognize him as different. Later I found out he had several overlapping diagnoses – cerebral palsy, epilepsy, intellectual disability, challenging behaviour – and he was difficult for his family and wanted to be independent. So they would help him apply for services and he would go off to live in an institution, a "training school," or a group home. And they'd be told to leave him be for a few months, let him get adjusted and the professionals would tell them when they could visit.

Then, never more than 10 days later my grandmother once told me, they'd get in their big old car and go to where he was and knock on the door and insist on seeing him in their quiet forceful way and he'd be brought to them, drugged, or bruised, or

unkempt and hollow eyed. He'd burst into tears and they'd walk him out the door to their big old car, with threats ringing in their ears as they went.

My mother said that once she was with her mother and an invitation to a wedding arrived, addressed to her and my grandparents. My mother said, "Oh for goodness' sake – they didn't invite Jerry!" My grandmother said, "They never invite Jerry." "But that's awful, what do you do?" "I assume they've forgotten him and made an error. People get so busy with weddings and these kinds of things. And then I do this." And she picked up the pen and ticked off the RSVP box that said they would be coming and under her and my grandfather's names she wrote "and Jerry Missere." "That way," she said, "They won't feel badly when they realize they forgot him."

One day, when I was staying with them, I was waiting for him to come home. I was in the front yard, pacing, and I began to drag my leg and then the left side of my body and then I grimaced in the way that he grimaced. I walked in circles, my lamed foot pulling up grass and dust, making the kinds of sounds he made. I am sure I was trying to be like him – I adored him for so many reasons. I didn't even notice my grandfather drive up to the house, but suddenly he was flying across the grass and ran up to me and hit me so hard I was flung down to the ground, and then he shuddered, paroxysmal with emotion, ran back to his car and sped off. It was so fast and so unreasonable (my grandfather was the most gentle of men) that I wondered at different points if it had really happened? But if it hadn't happened why would I have imagined it?

Uncle Jerry has a disability, and that happened.

References

Briton, D. (1996). *The modern practice of adult education: A postmodern critique.* Albany, NY: State University of New York Press.

Bochner, A., & Ellis, C. (2016). *Evocative autoethnography: Writing lives and telling stories*. New York, NY: Taylor and Francis.

Cacioppo, J. T., & Patrick, W. (2008). *Loneliness: Human nature and the need for social connection*. New York, NY: WW Norton & Company.

Gergen, K. J. (2009). *Relational being: Beyond self and community*. Oxford, United Kingdom: Oxford University Press.

Goble, C. (1999). “Like the secret service isn't it.” People with learning difficulties' perceptions of staff and services: Mystification and disempowerment. *Disability & Society*, *14*(4), 449–461. doi:10.1080/09687599926064

Goffman, E. (1986). *Stigma: Notes on the management of spoiled identity* [Electronic version]. Retrieved from https://www.amazon.ca/Stigma-Notes-Management-Spoiled-Identity/dp/0671622447

Hersted, L., & Gergen, K. J. (2013). *Relational leading: Practices for dialogically based collaboration* [Electronic version]. Retrieved from https://www.amazon.ca/Relational-Leading-Practices-Dialogically-Collaboration-ebook/dp/B00CAAS89I/ref=sr_1_1

Hornstrup, C., Loehr-Petersen, J., Madsen, J. G., Johansen, T., & Jensen, A. V. (2012). *Developing relational leadership.* Chagrin Falls, OH: Taos Institute.

Jacquet, J. B. (2013, November 26). Does English use red thread as expression for theme? [Response to a question on a language forum]. Retrieved from https://english.stackexchange.com/questions/106430/does-english-use-red-thread-as-expression-for-theme#comment285846_139267

McNamee, S. (2014). Research as relational practice: Exploring modes of inquiry. *Systemic Inquiry: Innovations in Reflexive Practice Research*, 74–79.

Montuori, A. (2017). Forward. In V. Martin, *Transdisciplinarity revealed: What librarians need to know* (pp. ix–xvi). Santa Barbara, CA: Libraries Unlimited.

People First of Canada. (1993). *Our stories: The stories of some of the leaders of People First in Canada and a workbook for people first member to tell their own stories.* Unpublished document.

Price, M., & Kerschbaum, S. L. (2016). Stories of methodology: Interviewing sideways, crooked and crip. *Canadian Journal of Disability Studies, 5*(3). Retrieved from http://cjds.uwaterloo.ca/index.php/cjds/article/view/295/514

Reynolds, J. (n.d.). Jacques Derrida (1930–2004). *Internet Encyclopedia of Philosophy: A Peer-Reviewed Academic Resource.* Retrieved from http://www.iep.utm.edu /derrida/#SH7b

Rich, A. (n.d.). *Cartographies of silence.* Retrieved from https://poetrying.wordpress.com/2008/12/15/cartographies-of-silence-adrienne-rich/

Roets, G., & Braidotti, R. (2012). Nomadology and subjectivity: Deleuze, Guattari and critical disability studies. In D. Goodley, B. Hughes, & L. Davis (Eds.), *Disability and Social Theory: New Developments and Directions* (p. 161). London, United Kingdom: Palgrave Macmillan.

Titchkosky, T. (2011). *The question of access: Disability, space, meaning.* Toronto, Canada: University of Toronto Press.

Uhl-Bien, M., & Ospina, S. M. (2012). *Advancing relational leadership research: A dialogue among perspectives* [Electronic version]. Retrieved from https://www.amazon.com/Advancing-Relational-Leadership-Research-Perspectives/dp/1617359211

Wall, S. (2006). An autoethnography on learning about autoethnography. *International Journal of Qualitative Methods, 5*(2), 146–160. doi:10.1177 /160940690600500205

“We are caught in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly.” — Martin Luther King

Chapter 7:

Summary Discussion and Implications of the Integrated Findings

Abstract

This paper summarizes the findings of this dissertation and discusses their implications in terms of knowledge and potential practices. After reviewing the research question and methodology in the context of Canada's Truth and Reconciliation commission I examine current gaps in the research and how the collaborative processes of this research addressed these. Results of the research are examined and summarized, leading to conclusions and recommendations for policy, practices, and future research.

Introduction

I was asked to facilitate for an American organization wanting to know what matters to people with ID and what to focus on in their strategic planning. About 60 people with disabilities, their friends, families and staff gathered, and I started them off with a 10-minute drawing lesson. They learned to draw five recognizable things—which they took very seriously—and then were confident enough to proceed. They shared stories about connections and belonging—what worked in the past and what was working now—and documented each other's stories. There was lots of laughter and joy.

When it was time to talk about the future they froze. They were fearful and inarticulate given looming budget cuts to individualized services they depended on and had fought for. This, in the context of what seems like targeting of people with disabilities by their own President within anger-filled conservative agendas that posit them as unwanted dependents. The narrative of rights attacked and increased marginalization had intensified each week over the first 150 days of the new presidency until, just before this event, self-advocate protesters were dragged from their wheelchairs, assaulted, and arrested and taken into custody (Crunden, 2017). They flinched at the request to think of the future.

Holding space in the discomfort, I breathed through my own fears in a difficult moment of facilitation. I find myself thinking about Fraser and Gordon's (1994) "A Genealogy of Dependency: Tracing a Keyword of the U.S. Welfare State," in which the authors trace how a word changes meaning through U.S. history, demonstrating how something that had signified a relationship of mutual respect and interdependence

turned into a weapon. This moment is not the first hard moment in the history of emancipation of people with disabilities. I asked them to remember the stories they had shared so far during our day together, think of those successes.

We talk about the power of a half century of history in their movement, instantiated in these particular best practices of this organization, and how, while the times are certainly frightening, a way to keep our eyes on the prize is to get ever clearer about what we want. As we continue to move towards clarity, I suggest to them, “Let us think in three dimensions.” I give them pipe cleaners, and they begin to build 3D models about their desired future. One group makes an altar to the idea of people with ID working at real jobs for real pay. Another takes a further step towards the performative and dresses one of the group in a garment made of pipe-cleaners that represents inclusion, accessible transportation, and housing. They’ve made her a torch and claim she’s the new statue of liberty. Another makes sets of glasses of pipe-cleaners so that we can all see the same future.

In one group a young man who does not speak communicates his vision of being heard by more than just those who love him, and the group builds an iPad out of pipe-cleaners. While they do this, one who knows how helps him to create his first subtitled video about his dream. Shyly, he moves from table to table, showing the video. What seemed moments ago like a vision of the future begins to happen in the moment.

I watch how leadership flows around at each table, then leans into and energizes the table next to it, and then the room. People who have not spoken are speaking, people who are known are being asked to contribute something they understand better than the rest of the table. Some people lean back and let go; others move in and facilitate. The room is loud and hot (the temperature has gone up to 90 degrees and there is no air conditioning), but they are determined. No one is leaving. In fact, new people trickle in. They are telling stories, laughing, listening, helping each other. They are leading together into the future by leaning into their dreams. During lunch the board members of the society find and sort the themes in the day’s creations and we make a gallery. In the afternoon we build on these ideas with more concrete planning about

who will do what, when. As one of the participants later says on Facebook: “Helping others helping each other.”

At the end of the day, a woman calls me over to take a picture of her and the drawing she has worked on. Each word is a laborious exhalation. Take. My. Picture. Please. I do, and show her.

“Well. That’s. A. Surprise,” she says, smiling softly.

“What do you mean?”

“On. A. Day. I. Am. Included. And. Heard. I. Have. My. Picture. Taken. And. I. See. I. Have. A. Disability. . . . I. Forgot. That.” She is not upset, just aware. I tell her I am glad we live in a world where people are different from each other, and we don’t spend nearly enough time celebrating diversity. She nods. She knows I believe this. “It’s. How. I. Know. There. Is. A. God,” she says. “He’s. Very. Imaginative. Thank. You.”

The people around her at her table are leaning in, obviously smitten and dedicated. The feedback on our day together has already been great, but it is this moment that we will remember. An imaginative god has made her a leader and with her network they are ready to move forward together.

Summary of this Research

This research asks the central question of what works to support people with intellectual disabilities as leaders in their lives, groups, and communities. The research was collaborative and involved people with ID as advisors, co-facilitators, participants, and co-researchers. I locate myself in the tradition of self-advocates and allies who believe that every step away from those the research is concerned to investigate creates further opportunities for misunderstanding and misguided assumptions, and every step towards a relational perspective leads us closer to sharing and understanding useful truths.

The central research question addresses a gap in the lack of research about the leadership of people with ID as leaders. Far more research exists on how those who serve them can be better leaders. There is little research about leadership from the perspective of people with intellectual disabilities. Even less exists that is based on

questions they have co-created. Our collaborative approach led to many insights. For example, the breadth of leadership as the maintenance of actively overlapping roles through one's life, groups and communities, comes directly out of these conversations. People with ID were also instrumental in this research's focus on the porosity of the interweaving ideas of storytelling, voice and self-advocate history and how these play into their opportunities to lead in authentic ways.

The form of this dissertation.

These collaborations shaped the methodology and also the form of this dissertation. Charged with thinking through how storytelling works for people with ID required sorting self-advocate stories, in the forms of often self-published biographies, from the larger literature review. In search of contemporary corollaries from younger self-advocates we found ourselves without similar self-actualized stories but instead, sifting through self-advocate statements embedded within agency and government documents. The fervent, committed writers of the previous generation, writing for a future in which people with disabilities would be included and autonomous, had been replaced by spokespersons and agency-driven peer evaluators within a narrow range of approving sound-bites. This became Chapter 2, "Ongoing voices of isolation and marginalization of people with intellectual disabilities supported in different kinds of programs: The 'cocoon of impossibility.'" The idea of how effective and possible accommodations such as graphic recording, which speaks to low literacy rates, works to include groups of diverse learners then became important to document as an answer to the implicit question of how might to include leaders with ID. This became Chapter 3, "Sensemaking to support leadership through arts infused person centred and inclusive planning processes." The ideas in this chapter also speak to the methodology of the research, which included graphic recording in every part where people with ID were present.

Chapters 4 and 5 might be seen as bookends to the idea of inclusive research about the leadership of people with ID. Chapter 4, "The Nearly Lost History of the Lower Mainland Community-Based Services Society: A successful self-advocate initiative,"

describes a successful organization envisioned, built and sustained by self-advocates. However, it also asks what happened to this organization and why this part of their history has been almost forgotten. Chapter 5, “A Meta-circle of Leaders with Intellectual Disabilities Discuss What is Helpful in the Leadership of their Lives, the Groups they are Part of and in their Communities,” brings all of these conversations together to address the central research question. The five community conversations in which more than a hundred people talked about their successful and satisfying experiences of leadership in their lives, groups, and communities are rendered into themes that provide the basis for a conversation that is informed by all the parts that precede it.

Finally, Chapter 6, “Röd tråd: A parallel story of leadership as the discovery of self, other and history – an autoethnography,” moves into how this research, and these relationships, have affected me personally and professionally. It indicates through the example of my own life, and generational truths gradually unveiled to me, that disability is really merely difference, named and defined in certain ways by systems and in other ways by people with disabilities and those who care about them. The medical model’s conceptualization of disability has always been refused and refuted by some, and yet the narrative is so entrenched that those we support to resist, and their networks, become what Titchkosky (2011) terms the “always-absent-present” (p. 90). What we see, and become distracted by, poised for argument, is that people with disabilities are governed by unwritten policies based on subjective theories of incapacity and vulnerabilities built over decades. As self-advocate leader Roland Johnson (1994) once stated near the end of his own autobiography, which might be the first of its kind: “Who makes these laws [that govern people with disabilities]? Who writes them? Nobody” (p. 96).

The implications of Canada’s Truth and Reconciliation Project.

This research, as with everything in contemporary Canada, is done in the context of the most important conversation in our country. The Truth and Reconciliation Commission (2015) seeks to address historic and contemporary ways in which first nations peoples have been treated. Two things come into play within its 94

recommendations. First, that indigenous peoples have been badly used by in systemic ways and this must be redressed in our time, and addressed as part of our history. Second, those of us who are not indigenous must come to terms with the actions of our forbears, and with our own often deeply buried assumptions. Truth and reconciliation is not simply the concern of a marginalized people and a government newly intent on fairer representation, but a need for each of us if we are to be whole, and part of a whole country. Equally, it seems to me, for us to be complete as persons and communities we need to include everyone, everywhere. At the end of this research it seems even more important to me that people with disabilities are not just bussing tables at Starbucks, but participating as leaders.

The Research Questions

The primary holistic objective of my research project was the collection and thematic organization of stories of some people with intellectual disabilities of experiences of leadership that they had found successful and satisfying in their lives, in groups they belonged to and in their communities. Self-advocate advisors helped shape the question, turning it into "plain language" by using different, shorter words, bullet points, definitions, and a focus not on "success" but on what felt satisfying and successful, communicated through stories:

> *"Leadership means to take action. What are some stories about what has been satisfying or successful for you as a leader in:*
> 1) *Your life*
> 2) *Groups you belong to*
> 3) *Your community?"*

Over the course of the earlier research they also added secondary questions as we began to review how the research methodology might work:

> A) *How are self-advocate stories shared when they are asked about their successes?*
> B) *What "worked" to make the Lower Mainland Community-Based Services Society successful, and what might be learned that would be useful for similar future projects?*
> C) *What works for self-advocate leaders in the leading of their lives, groups they are part of and in their communities?*

These three secondary questions allowed exploration and reflection on more than 30 years of leadership experience accrued through People First and in other groups of people with disabilities and diverse leaders. Looking at how self-advocate stories are shared allowed us to look at the literature they have generated, both autobiographies and “interstitial stories.” It made us aware of the importance of invitation in a few ways – from their stories, we could see who held the power of invitation and often what the agendas were. In the Derridean sense (Reynolds, n.d.), we saw who was “hospitable” to their stories. This also allowed for the exploration of how graphic recording worked in self-advocate storytelling and how it has been used to generate personal and community development. All of these ideas fed into the primary concern to collect stories of what worked in their lives, groups and communities to support them as leaders.

Collaborative questions: Explicit and implicit.

It was important that the first act of our collaboration was to co-create these questions. The questions have explicit and implicit elements. On my own, I would have, with good intentions, researched another project entirely—something like how can non-disabled allies better support self-advocacy groups? This more defined and smaller question would be conducive to a kind of reductive, error-free research (Briton, 1996), but would not have been a “true” question reflecting the concerns and thinking of this group of people. The very heart of how leadership is defined by them would not have been represented. Their meticulousness in insisting that leadership happened through the ways they lived their lives, their groups and their communities, and that “stories of successful and satisfying” leadership experiences were what mattered to them, directed this research.

Gaps in the Existing Research

The research question addressed gaps in the research. First, little is known about the ways in which people with ID were leaders and what best supported them, and, second, what they think about leadership and what has worked for them? While not

many examples of research addressing self-advocate leadership exist, that which does exist has rarely been produced through open-ended dialogues with people with ID.

Methodology

The methodology of this research might be referred to as a bricolage. Social constructionist research methods and social constructionist ideas, such as interdependence, a focus on language uses and the dynamic construction of relational realities informed these processes. Participants requested from the beginning that the research be useful to them, and that it be almost immediately accessible. They had experienced research that was not useful, and was not returned to them, despite promises to do so, and often this seemed to be because academic processes slowed down timely interactions.

At different points, research processes were discussed with participants. Gergen's (2015a) idea of research as "future forming" (p. 287) was a favourite topic and in at least one instance was brought up as a rationale to argue assertively for the exploration of what might otherwise have been seen as a side-line in more traditional research. In another conversation we discussed his metaphor of traditional research as a mirror of what is, while the aim of social constructionist research was to help participants see what could be. Participants enjoyed these philosophical and somewhat abstract discussions, particularly as they were easily rooted in their own realities.

Graphic recording was considered to particularly speak to this idea of creating a vision that participants could understand and move towards, immediately. Constant dialogues in workshops and other kinds of conversations also allowed for a growing understanding of the body of knowledge we were creating. Graphics of their iterative conversations were distributed through social media. Individual participant worksheets that could be filled out during our workshops and then taken home to be shared locally were another way to initiate change through rapid templating for a leadership lens on inclusion, empowerment and belonging.

Inclusive and relational research.

Social constructionist theory interweaves well with the methodological and ethical perspectives of inclusive research (Walmsley & Johnson, 2003) and what Bigby, Frawley, and Ramcharan (2014) refer to as collaborative research. An aspect of this that was particularly appealing was the idea of reciprocity—that in these processes we are all learning about ourselves and each other. To engage specifically in "research" allowed for new entryways and exits within an understanding of the self and each other:

> *Each time we engage with others and our environment, the possibility of creating new meaning and thus new worldviews is present. What is interesting about this is that we are largely unaware of how persistently we work to maintain the sense of a solid, stable, and continuing worldview. Without our own participation, these worlds of research and the inevitable version of reality they produce would not endure. We are the ones who maintain these realities, these standards.* (McNamee, 2014, p. 79)

Their involvement in the co-creation of the research questions and the design of iterative processes also made them excited and determined to be actively part of the research and to make sure their friends and colleagues were involved as well. This process of peer introduction/invitation was incredible in that it welcomed a wider range of participants—people who were non-verbal, those who had not thought of themselves as leaders, people with stories they had never been able to tell. This reflected the insistence of self-advocates that everyone belonged, everywhere. The initial concern that the research might not reflect a cross-section of people with ID disappeared when their peers were given responsibility for participant involvement.

Requests for updates came in at least monthly. Often, people already knew our names when they came in and introduced themselves as friends of friends. Many participants entered the room knowing this was "their" research (based on "their" questions) and that the dialogues would be returned to them. Others brought parents, allies, and staff with them, as they wanted them to understand the implications of the research.

Critical disability studies: A lens to interdisciplinary reflection.

Dan Goodley (2013) writes that the "critical" (p. 632) in critical disability studies leads us to self-appraisal and a sense of ourselves as social creatures, within society, as products of our histories and as people looking towards future possibilities. Critical disability studies are also considered to be necessarily interdisciplinary (Goodley, 2016), and this matters a great deal, given the historic damage done to people with disabilities through single lens research out of professionalized disciplines (e.g., Smith & Wehmeyer, 2012; Trent, 2017). Critical disability studies, as part of critical social theory, "views the working of society and culture as much more dynamic than what can be captured quantitatively. Undergoing continual historical and sociocultural transformation, society cannot be described adequately without reference to changing social relations and cultural meanings" (Meekosha & Shuttleworth, 2009, p. 52). In the end interdisciplinarity as a feature of critical disability studies creates an opportunity to look more holistically at the intersection of life and research for people with ID.

Results

There were a range of theoretical, operational and strategic results in this research, some of which overlap in their implications. In general the research demonstrated that people with ID have important feedback to provide about how they can best be supported to lead in their lives, groups and communities. This is demonstrated in the collection of their ideas through a literature review of their narratives, an exploration and analysis of one of their projects and of some examples of inclusive planning for persons and communities, their discussions in the community conversations about leadership and while working with the meta-circle and advisory group of self-advocate leaders.

The research itself is a demonstration of how results are improved by the inclusion of people with ID in leadership roles, but there were also many stories throughout the different parts which indicate this. Particularly in a world of diminishing resources for social supports this is important as it allows those supports to be focused where people want them.

Accommodations.

In this research we became more clear about the need for *consistent* accommodations. First, accommodations of various kinds, often suggested by participants or their peers, made the authentic inclusion of people with disabilities possible in this research. However, participants reported that even successful accommodations were often unreliable and inconsistent. Even the simplest accommodations, such as large print for those with visual disabilities, were unreliable. One participant, legally blind, said that he appreciated people making large print documents for him, but was puzzled and frustrated when they would share things with him that he could not read, without any rationale. This made him feel that it might somehow be his responsibility to make sure he could access the materials they had invited him to discuss.

Interestingly, in one session he wanted to “walk through” the graphic recording we had made and we were able to quickly add tactile cues so that he could do this by touch. He talked about similar situations in which he was less comfortable making such suggestions. Without access to the notes that everyone else had, he could pick up on at least some of the proceedings, and this was better than not being invited (which would mean that he and his peers were not represented). However, participants also wondered what such situations indicated about their inclusion? Were they token participants? If they complained would they be excluded in the future?

The concern is that if even the strongest, most assertive self-advocate leaders have difficult broaching these concerns, what happens for those who are new to leadership or less assertive. Another strong leader talked about participating in groups that would agree that plain language was theoretically necessary but then use complicated words: “It’s exhausting to keep reminding them.”

Skilled self-advocate leaders.

It was apparent that many self-advocates involved in this research were already skilled communicators, planners and facilitators. They were also hungry for new information and new ways to learn. One result of this research was that involved

participants became more skilled at thinking holistically about different aspects of their lives. They became better questioners, and more assertive. They had several new ideas they suggested as research projects, and continue to bring up new ideas.

They also had many more opportunities to facilitate, both at the front of the room and in small break-out groups. When one of the quietest participants spoke at length and with clarity about leadership and intellectual disability, and his peers asked where he had learned to do this, he said, “Well, you keep inviting me to these things, don’t you?”

The pedagogy of leadership learning.

There were many indications that hosting a continuum of focused open-ended conversations about leadership as a lens on different roles in their lives was beneficial to participants. First, they were fascinated by the idea that they have an important leadership history, much of which was unknown to many participants. Second, they were interested in the idea of clarifying how they are leaders, as their intuition was that this happens differently for them. Third, there were many opportunities to share their own experiences and learn from each other which participants felt were very valuable.

Individually, participants were able to bring in ideas that mattered to them, such their feelings and questions about tokenism. This led to conversations about things like how one might know one was being tokenized, for example, which eventually led to exploring models of participation from youth-involved groups (no similar models were found in disability related research) and the modified clarity model which begins each chapter of this dissertation. One such discussion led to participants returning to an advisory group they had been asked to participate in and asking for the terms of reference.

Stories.

A significant finding of this research was the importance of storytelling as a method for conveying goals, inciting leadership, explaining opinions and ideas. However, we also learned about important stories gone missing, other stories being

ignored, autobiographical stories being disempowered through a systemic kind of editing for inclusion, and many, many stories waiting to be told, collected and discussed.

Most of all, there was a sense of stories misunderstood, misrepresented and held up to criteria which might differ from those of people with disabilities:

> *Stories about us are boring. As predictable and ubiquitous as they are dangerous, normate narrations of our lives are as straight as they come: one-dimensional narratives of tragic loss and/or progressive normativity. We are dying or overcoming. We become a burden or an inspiration. We desire vindication or marriage. Our entire narrative worlds are defined by our Otherness, yet revolve around the normates and the normative. These stories cut straight to the point, using—and used as—well-steeped, easily readable metaphors bolstered by the requisite piano-based musical cues. If we didn't know us better, we would bore us.* (Pierre & Peers, 2016, p. 1)

An implicit question in all of this was why did stories matter so much? Initially my assumption was simply that stories level the playing field for us all. For me, they were interesting but also would be the vehicle of the data to be collected. As time passed, I realized this was reductive and that stories for this population mean far more than this. They were a teaching tool, although sometimes not understood by those self-advocates hoped would learn from them. Thus, their value was approximate, tentative, and potential, but also historic.

In the first project of the newly established People First Canada, Our Stories: The Stories of Some of the Leaders of People First in Canada and A workbook for People First Member To Tell Their Own Stories, the authors begin by defining history: "History books are usually about important people and events which really made a difference. This is a history book." Then they move on to connect the idea of history, the story of people who made a difference, with their own stories:

> *People First members are important people. They do things that really make a difference. The history of People First members and groups is important.*

They then invite storytelling within this context:

> *We think it is important for People First member to tell their stories. When we tell other people our stories, we tell them our history. We tell them about important things that have happened.*

> *When People First members tell each other their stories, we learn what we have gone through. . . .We find out what we have in common. We find out all the different things that can happen. . . .*
>
> *Our stories help us find out how things can be different. You hear about how other people have dealt with issues just like your issues.*
>
> *When you tell other people your story, they learn what life is like for you. They hear about things we can do. They begin to think differently.* (People First of Canada, 1993, p. 1)

Thus, stories were part of the historic culture of people with ID from the beginning of their interactions with community allies. Stories about stories, and stories about storytelling initiatives went back to the beginning of their recorded history. It is unlikely that such a significant aspect of their culture was simply born because allies were there to listen and support their story telling, and it is likely that stories were a vehicle for various kinds of signifying in institutions.

Contemporarily, the act of telling stories was intrinsically relational. It allowed them to see who was listening and paying attention, and perhaps even who was trustworthy. They were a way of offering a whole self. Without this instruction, I do not think I would have focused on their stories in the same way. While narrative research has always appealed to me, I think I would have played it safer and interviewed a select group of self-advocate leaders using a semi-scripted format.

Another implicit question from self-advocates was why their stories were not having the effect we hoped for? In part, without context, the stories each exist alone. They do not make what Hagel (2013) refers to as a narrative with a "persistent context" (para. 1–3) that can frame a new story and a new theory of disability as having leadership capacity. As Simplican (2015) points out, these stories often require a fuller experiential context that involves self-reflection on one's own privilege and for one's own relationship to people with disabilities placed within the intersectionality dynamic. This might not end with concrete knowledge:

> *My understanding of the Fellowship Group and my own role in that understanding remain problematic. First, how members understand themselves and how they value self-advocacy remain open questions; my observations give*

> *us no insight. Moreover, signs of my own ableist and race privilege are evident in my narrative analysis. As I reread the story I have written, I become more aware of the fact that I knew the names of the white professionals and advisers but not most of the members — even the members who spoke during the meeting. Why did I not transcribe or remember their names? I could rewrite the narrative to make my lack of knowledge invisible — to try to disassociate myself from my race and ableist privilege. But I choose to leave it intact — an unwanted signature.* (Simplican, 2015, p. 108)

We see here the complexity of being allies in this world-building through storytelling. Further, we become aware of the necessary infrastructure to create a "persistent narrative" that is meaningful.

In Chapter 2, "Ongoing Voices of Isolation and Marginalization of People with Intellectual Disabilities Supported in Different Kinds of Programs: The 'Cocoon of Impossibility,'" we see the opportunities for the kind of self-driven life stories that were told post-institutionalization seem to no longer exist. Further, the interstitial comments made by people with disabilities about their feelings of segregation as they were invited by those in authority to speak have very similar imagery, language, and psychosocial outcomes. This alerts us to three related issues. First, that storytelling is a consistently identified way over a period of about 50 years that people with ID as individuals and as a culture have conveyed their histories, contributions, and goals. Second, there can be significant issues of power and control in the way people with ID are invited to participate in storytelling by those in charge, even though it is, so to speak, their language. Third, that people have previously been supported to tell compelling stories by various kinds of scribes in and out of organizations in mostly local ways alerts us to the possible wealth of self-advocate life stories that may exist, which are undocumented and should be of use to scholars in all kinds of disability related fields. One can only imagine the power of networked self-advocate stories from all around the world. Fourth, academia has made little use of such stories as the fodder for research. For example, given the focus on inclusion in school systems in Canada, where children with disabilities theoretically spend at least 12 years of their lives with, theoretically, their peers, should we not know what they felt was beneficial or challenging?

Critical Reflections

Truth and reconciliation as a model of changing leadership.

As Justice Murray Sinclair (as cited in the Truth and Reconciliation Commission of Canada, 2015) states, “Reconciliation is about forging and maintaining respectful relationships. There are no shortcuts” (para. 17). This has many implications for this research, not least of these is that stories of successful and satisfying leadership for people with ID are often stories in which no one took shortcuts.

So, for all Canadians, truth and reconciliation is not “another subject” or a side project, or a temporary excursion from some main point, but our context. We are once again, as Al Etmanski (2015) has said, on the “spirit canoe” (p. 1), but this time there is “room for . . . [all]” (p. 1).

Indigenous people have moved from the back of the room, if, as with people with ID, they were invited at all, to being at the forefront of initiatives that are bringing people, the environment and social problems together in astonishing new ways (Suzuki, 2017). They do this with a new kind of gracious, transformational (for us all) leadership. This would have been unthinkable in my parents and grandparent’s time.

There are many parallels between the story of indigenous people and those with intellectual disabilities (Roman, Brown, Nobel, Wainer, & Young, 2009). Both were removed from their families and communities and placed in institutions. First nations children were “scooped” and taken to residential schools where many were abused, and from which many did not return. The families of people with disabilities were told to forget them, and given no alternative supports to make having them at home possible, and then taken to institutions that were also called “schools” and many were also abused, and all were wounded and traumatized (McCallum, 2001).

While not intending to compare the experiences, or to suggest these are not both singular stories, there are resonances in the ways both groups suffered systemic marginalization. There is also the possibility to examine potential parallel pathways into a future in which leadership is more broadly inclusive. Indigenous leadership differed so much from Euro-American concepts of permanent, democratic or hereditary leadership

that it led to significant misunderstandings as colonizing Europeans sought binding agreements with those they assumed were their counterparts.

As the conversations about Truth and Reconciliation continue, it becomes apparent that indigenous leadership differs from Colonialist assumptions about what leadership is. Asked to describe leadership, Musquem Elder Rose Point says,

> *Leadership does not start all of a sudden in adulthood. Leadership training starts at a very young age. Leadership is being able to help people that are in need, being friends with people, as your peers; looking at what things that need to be done and making the effort to make sure things are done; never making comments today to anyone or to say anything wrong to anyone that you might be sorry for tomorrow.* (Point, 2011, p. 5)

She tells a story about walking most of the night as a young child with her aunt, through snowy woods, to visit someone who was ill. Being present and helpful is leadership, and is perceived as a gift, and the story of this experience is one of the signature teachings of her aunt which later made it possible for her to become an elder and leadership educator in her own community despite living through horrific marginalization (Point, 2011, p. 5).

In the conversations that have ensued, while there has been a tendency for those of European ancestry to avoid dialogue, indigenous peoples have welcomed it and taken proactive leadership (Macdonald, 2017). What we now recognize as indigenous leadership immeasurably changes our vision of what the world is and of what leadership is. Reconciliation is transformation. The implications for the study of people with ID and leadership are that, similarly, we may also only be beginning to understand what leadership for people with ID looks and how it is different from what we expect.

Like indigenous people's leadership, the complexity of leadership in the lives of people with intellectual disabilities is interwoven, as in so many other parts of their lives, with issues of agency, independence, and interdependence (Ashby, Jung, Woodfield, KatherineVroman, & Orsati, 2015). What's far more recognizable and accepted is that indigenous people are a culture, whereas people with ID are not usually thought of in this way:

> *I am using the term culture to describe an Aboriginal worldview (paradigm) that informs our ways of thinking (epistemology), knowing (ontology) and guiding our interactions (axiology) with the world (Wilson, 2001; Steinhauer, 2002). These diverse Indigenous paradigms or Indigenous knowledge systems contribute to the field of leadership and education for all peoples. Indigenous Knowledge systems are ecologically centred and affirm the inter relationships between people, communities and ecosystems (Nadeau, 2005).* (Young, 2006, p. 2)

Of course, it is true that indigenous people's culture have, among many features, "the accumulated shared learning of a group based on millennia of communal expertise" (Young, 2006, p. 2), but it may also be true that people with ID have generational experience, passed down from older to younger in the way that Horwood's (1987) novel, *Skallagrigg*, suggests – communication simply coded for the actors with disabilities, in some way we do not understand as observers.

Relational leadership – leading in a circle.

To recognize leadership in another culture, we must know what to look for. The concept of relational leadership is relatively new as an area of research, and yet has existed in various cultures and subgroups throughout history. Signs of relational leadership found in this research were the synergistic actions of small and larger groups of self-advocates and allies, relying on each other's strengths but also leaning in to support challenges and deficits. In this way they were able to accomplish more together than they would have as separate entities. This is seen in the stories, auto-biographies written with support, the creation of LMCBSS, the methods for meeting in PATH and other sensemaking dialogues and in their history of leadership activities. The contemporary sense of how relational leadership functions is supported by the conceptualization of self-advocate leadership as a complex, communal, context dependent role (Roets, 2009; Goodley, 1997, 2000, 2005).

The impact of a perceived lack of leadership.

Just as the absence of recognizable indigenous leadership indicated a lack of sovereignty and a perceived need to be externally governed, so did what was perceived as a lack of leadership qualities in people with ID require supports and governance, and the two almost from the beginning were enmeshed. Very quickly, and to a continuing

extent, supporters became oppressors. Leadership is considered to be the province of everyone but those being served (e.g., Luetke-Stahlman, 1997).

In identified models of disability (Berghs, Atkin, Graham, Hatton, & Thomas, 2016), such as the religious, charitable, medical, social, and human rights models, little attention has been paid to existing leadership of people with ID or to consideration of leadership as a potential factor in their emancipation. In fact, an emancipatory model that would require leadership, as self-representation, in groups and in communities, is not much discussed.

Measuring efficacy.

In this approach to research, one measure of success is whether the research has contributed to the bodies of knowledge about people with intellectual disability and leadership, but another is whether through these processes the skills of the participants have grown and allowed them to make changes in their own lives.

As we met with groups to talk about leadership and this research, Liz asked for support to create and lead her own workshop: "Drawing Big Dreams on Big Paper," about how she has used her art work to convey her dreams and engage her family and friends to support her. She has successfully presented this workshop several times.

In terms of leadership in her life, she asked for assistance in person-centred planning, and I was honoured to be a facilitator at her PATH, where I got to meet family and friends who were important to her. They were excited to ask about our work together, which they had heard about.

Barb already knew a great deal about leadership when we started working on this project, but began training to become a "seniors' ambassador" in her community, and many of the ideas that we were discussing in the research process were clearly expressed in an article she wrote: "We are all leaders. Now we are becoming leaders who are also seniors" (Goode, n.d., para. 14). Barb also asked for support to help commemorate one of the most important events in her advocacy career, the landmark Eve Case in which the Supreme Court confirmed for the first time that people with ID have control over their own bodies, and we created a graphic about this story (see

Appendix E). Again, this might have seemed a detour but the documentation served both our purposes in several ways. Not least of these was that it contextualized another later conversation about successful self-advocate generated materials to support sexual health which she found particularly satisfying. In response the University of British Columbia recorded an interview with her and created a website to commemorate the Eve case. Barb was also able to use the graphic of the Eve case in workshops, and as a handout in the program for a disability related film festival.

Becoming researchers.

This research points out the possibility of participatory action research as one way to speak to the needs of self-advocates to build in capacity for debriefing their experiences and initiatives by developing trustable relationships with those trained in the ethics and processes of inclusive research. It also points to the potential for growing their own skills for self and collective reflection in ways that are empowering. These methods could be mastered by those on the receiving end of service-driven and institutional assumptions to become capable of greater agency and self-efficacy.

Self-advocates participated in planning the research project and were consistently interested in how research might serve them, as well as wanting to finally understanding what happened. They were supported to learn new skills around project management, facilitation, listening, data collection and presentation. A significant difference in this project is that this research question came directly out of their dialogues and our relationships, and the processes used to examine it were emergent and open-ended. We did not know what we would find. For example, an early question of the LMCBSS research was whether self-advocates might create a new society, and some participants hoped for this within our project. Instead, they decided that they did not want to repeat their experience, remembering that some of them had ended up hesitant even to sit on other boards after. Further, they realized that issues for younger self-advocates have changed, to focus on different kinds of inclusion and empowerment, even though many of the same conversations about being disenfranchised continue so many years later.

Summary

People with intellectual disabilities have a relatively unacknowledged history of more than 40 years of leadership as People First Canada, sponsoring and supporting self-advocate driven projects in every province and territory, and engaging with government at all levels (People First of Canada, 1993). For people with ID the potential to have a culture has been heavily overshadowed by the systems they are supported by, as John McKnight (1995) writes,

> *Our problem is not ineffective service-producing institutions. In fact, our institutions are too powerful, authoritative, and strong. Our problem is weak communities, made ever more impotent by our strong service systems.* (p. ix)

The idea that people with ID might be rationale and possess qualities of leadership is so embedded that when critical thinkers George Lakoff and Mark Johnsen (2003) deconstruct the metaphor, “Life’s . . . a tale told by an idiot, full of sound and fury, signifying nothing” (p. 174), almost word by word as part of their book on language and imagery, they completely ignore the word “idiot,” so certain are they of our shared understanding of this concept. That supposed shared understanding absolutely denies the potential for leadership: “full of sound and fury, signifying nothing.”

Research for this dissertation examined the way that story and language influences people with ID in the leadership of their lives, groups and communities. We see here evidence that widely vaunted programmatic changes during the transition from institution to community inclusion programs have not increased people’s sense of inclusion as much as would be hoped. The supports in place to foster inclusion often create the tools for isolation. Self-advocate leadership is a rich resource out of which people can take more control over their own living situations and destinies, come together as autonomous groups and demonstrate remarkable leadership skills that would be of benefit to their communities. In many situations, people have done and are doing just that, but without a persistent narrative to contextualize their successes they continue to be seen as individual and exceptional.

In our culture signifiers of leadership are evidence of ultimate competence: people with the qualities we think of as leaderly are those who take charge of their lives,

create social change, become entrepreneurs and are looked to by others for direction. In this research it became apparent from the first conversations that people with ID leadership might differ in conceptualization and practices. An interesting aspect of leadership for people with ID is their consistent sense, from the beginning of our research, that it is as important to pay attention to the way in which they "lead" their lives, and the energy it often takes to negotiate with systems, parents, and very finite finances as it is to attend to who is at the podium and who leads the parade. In the initial meeting of the first advisory group participants told me that to not think of the constant work of "leading" their lives as acts of leadership was an act of privilege.

In their day to day contexts the mysteriousness of the word "leader" as "to go forward" in relation to people with intellectual disabilities seems singular. In our own lives, we *assume* that we will "lead" our lives – we "go forward" to make decisions about where we will live, who we will associate with, where we will work and volunteer, and what we will aspire to, and assume that our networks and supports will follow us or not, but their responses won't be to question our ability to make such decisions. For people with ID a kind of diagnostic foreshadowing creates conditions for "the soft bigotry of low expectations" and given that they depend on organizational entities for supports for accessibility, necessary financial supports and accommodations for inclusion which are organized, or not, their emergent leadership has always been both within and outside these and always influenced by them in significant ways.

If, as Goodley (2000) suggests, we can think of people with ID as a culture or subculture with certain shared qualities, it seems we know relatively little about the way they lead or can be supported in leadership. An intersectional approach, which considers a matrix of vulnerabilities and strengths, would suggest that our lack of understanding increases their vulnerability, reduces their capacity to build on their strengths and decreases their opportunities for inclusion at strategic and operational leadership levels. In Gergen's (2009) "Constructing the Real and the Good," he articulates the mechanisms by which people are controlled and act out of agendas of beliefs which play out in our language. He suggests that the worlds we inhabit are

constructions of our beliefs, and "we must be conscious that we are joining in the language games of our cultural traditions" (Gergen, 2009, p. 55). Self-advocates from the beginning of their introduction to this research concept told me that their leadership might happen in different places (such as where they lived and within their families) and might look different than what I expected to see, and yet as forms of leadership deserved equal attention and respect.

Conclusions

Ship of Theseus.

Plutarch tells the story of the ship of Theseus, replaced plank by plank as it aged, and asks whether the ship that arrives home is the same ship that left port? (Plutarch, 75 A.C.E.). Many aspects of the research point to the replacement of the planks that formed institutions with similarly constructed parts, merely moved into the community. There was and continues to be a tendency to infantalize disabled people that is exacerbated in services oriented relationships:

> *Jenkins (1989) . . . highlights the complexity of this identity in our culture, pointing out that although they are regarded as biologically mature or chronologically adult, the individuals are, in fact, regarded as non-adult in any intellectual, psychological or social sense (p. 105). Also, Dossa (1992) has addressed similar issues, focusing on life patterns and activities of people with `developmental disabilities' in the USA, evaluated by service providers as promoting independence. He argues that users of these services were actually maintained a in a state of perpetual adolescence, or at the level of a graduate from a home economics class (p. 6). These views concur with my own in respect of participants in this study [of the relationships between services and people with ID].* (Goble, 1999, pp. 459–460)

Self-advocate stories, in the paper the Cocoon of Impossibility, led to the question of what stories those who are in "community inclusion" programs would tell, if they could, and of how they are now less likely to be able to tell these stories and, in effect, either object to the roles that systems have constructed for them or suggest new roles. Prior to institutionalization, it was not possible for people to tell their stories, and they were punished for doing so; after institutionalization many of them did get to speak up, and wrote books and were assisted in recording oral histories.

Contemporarily, many people with disabilities are featured in various ways within the communications projects of the systems that support them, but it would seem that their hope of saying what they mean comes through ruptures and the interstitial commentary they are resigned to. Likewise, in the story of LMCBSS we hear about an entire agency created and run by people with ID, that was then enfolded in with other agencies to become part of the largest organization in British Columbia. People are invited to speak and invited to lead, but the planks that form the platforms they stand on have only been replaced by planks that control them in more subtle ways.

Self-advocates are encouraged to work within the systems that support them, as partners, but as is evident in these articles, this is not always a profitable course on the road to emancipation. Within partnerships that often feel awkward and unbalanced, there are no opportunities to debrief, learn from their experiences and object. Support organizations are predicative of how hard community inclusion will be, “the long road,” while seemingly unaware that they have their own internal, embedded barriers to inclusion and empowerment.

There is no overall consideration of people with ID as an emancipatory movement from within their services. LMCBSS was a singular instantiation of this idea, and their allies brokered and organized their demise. There are no tools to consider such situations except dialogues that will take as long as they take. The tools that systems focus on are designed for other purposes, but they are never designed to create the opportunities for larger conversations such as whether the systems themselves are necessary. For people with disabilities on a daily basis, this denial and assumptive concept becomes the work of interacting with staff who have far less experience of and opportunities for larger ideas.

An area of strength and resources are the stories of people with disabilities as leaders in their lives, groups and communities. Even this can be easily perverted so that we only hear the stories that reassure us of our beneficence. Yet the experience of this research is that people with ID want involvement. They are wanting authentic relationships, communication and opportunities to learn and grow, in the same way

other community members do. The potential for social constructionism is to deconstruct and dismantle the way in which disability has been constructed and imagined and assist the actual people with disabilities to share their stories and in the process write a new narrative of leadership involvement.

Our role as allies in this might be what Gerber (2017) suggests for academics in disability studies:

> *The world always needs the deconstruction of what is deemed the normal, and the most important place to start is the deconstruction of ideas about the normal body and mind. Why "most important?" Because of the many tyrannies that can overtake daily life and ruin our hopes and dreams, none is more insidious and devastating than being thrown aside, because there is a consensus somehow that the way we look, or think, or move or don't move, or hear or don't hear, or see or don't see, etc., should destine us to be discounted human beings.*
>
> *But that oppression is, at its core, part of a larger problem: how people who think they know what should be have come to that understanding, and why they persist in believing as they do. That such criteria for devaluing people and creating an Other are often completely taken for granted proves just how insidious they are, and hence how radical, as in getting to the root of things, is the work of those of us advancing the study of disability.* (para. 2–3)

Recommendations for Policy and/or Further Research

Nothing about us without us.

In each of the papers that comprise this dissertation some recommendations for changes to policy, practices, and further research are made. Overall, the most significant recommendation is for the authentic involvement of self-advocate leaders in every aspect of their lives, services and supports. The initial rallying cry of the disability movement was, "Nothing about us, without us," and just looking around in a room of decision-makers continues to be an effective test for organizations or projects supporting or including people with disabilities. If they are not there, why not? If one is invited to meet, why not commit to bringing a person who is served, as part of a partnership agreement.

Involving people with ID in research and development.

In particular, this standard for inclusion might be part of an expansion of research that more comfortably includes these new partners, in ways that are now common in the United Kingdom (e.g., Walmsley & Johnson, 2003). Further, focusing on the voices, and stories, of people with ID as they offer them, rather than in our often well meaning but misguided translations. As bell hooks (1990) has written,

> *No need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I rewrite myself anew. I am still author, authority. I am still the colonizer, the speaking subject, and you are now the centre of my talk.* (hooks, as cited in Walmsley, 2004, p. 65)

What self-advocates co-created in this project was the idea of a research practice of iterative processes during community conversations of open invitations, informing, educating, questioning, hosting dialogues, while concurrently collecting information and analyzing themes. The gathered information was then delivered and potentially taken up by the next group in the next community conversation, and in the end the whole was reflected on by the meta-circle of leaders.

Research and development partnerships with embedded facilitators within organizations, trained in research theory and inclusive research, or organizations working in partnership with universities and colleges, would created local bodies of gathered information that would be useful to people with ID and those who support them. These partnerships would include people with ID as collaborators.

Leslie Roman (2009) has pointed out,

> *In terms of work in the area that addresses qualitative issues, methods and ethics in education, disability is often the last stop on the social justice bus, if the bus stops there at all. And, we might then ask: "Is the bus ramped?" . . . "Does talk of inclusive education [or community inclusion] go far enough to meet the material and political needs of people with disabilities?" How would qualitative research look done by, with and for disabled researchers about the workings of ableism?* (p. 3)

Inclusive research, as it is practiced in the United Kingdom (Walmsley & Johnson, 2003), and its variants around the world, seems a way to incorporate feedback from those closest to services and their communities about the needs for change. Importantly, such research projects begin with the agenda of the researchers with disabilities and work collaboratively throughout.

Currently, the orbits of research and service provision for adults do not act in conjunction with each other because, not least, neither has a commonly understood role in people's lives. One is assumed to be the province of professionals and academics – perhaps the most distant of worlds to that of People First's insistence on plain language. Non-profit service providers, who once acted as charities on behalf of people with disabilities as advocates, have become increasingly involved in entrepreneurial business that makes clear sighted analytics problematic, unless they are in favour of the continuing growth of service providers and government agencies (Duffy, 2016; Pallotta, 2009, 2010). Constantly at the behest of governments and scarce funding, there is little time to think critically about negotiating the particular personal and cultural histories of those served. Neither is there consistent planning for a longer-term future in which they might assume mastery of what currently serves them.

Family dynamics and leadership roles through the lifespan.

There are indications in other research that family leadership roles occurring pre-school age create a set of memories of leadership qualities that can be accessed later in life, no matter what has happened in the intervening years (Johannes, 2011). In this research there were also some indications of the family as a positive influence on the person’s leadership capacity and confidence, and of parents as allies, but there were also implicit questions beyond the scope of the current research:

- “If people have a caregiver they might not get heard – their parents or their caregiver might take over.”
- “In the old days parents were supposed to speak for you” [but now] “I can speak on my own and I have my own accomplishments.”

- “The parents think they will listen to the [self-advocacy] group, not the parents if they go there.”
- “Parents can be very critical – [they make] some assumptions when people are trying to come together.”

Self-advocate leaders pointed out that one reason LMCBSS was singular was that all other local agencies were driven by parents' values, which were not always in alignment with their own. Perhaps even more simply, why were they themselves not the consultants on how these organizations operated? The final comment in the last focus group was that there would always be the need for self-advocate groups, as long as there were parents’ groups. Research into how the leadership roles of people with ID play out within family systems throughout the lifespan would be educative.

Narrative focused organizational development.

In this research, stories are the preferred method for self-advocate leadership. Stories are local, personal, dialogic, self-representational, influential, and motivational. While they are tools of self-advocate leadership they are also in their concreteness a limitation in many ways. The act of gathering groups of stories to find what Hagel (2011) calls “a compelling narrative” (Examples of Narrative section, para. 2) is one that self-advocates, suffering not least from a lack of educational opportunities, have acted on in intuitive ways:

> *A narrative has two key elements. First, it’s open ended – it’s driven by some view of an opportunity or threat out in the future that has yet to be achieved and it’s far from guaranteed that it will be achieved, but it is worth pursuing. Second, it’s ultimately not about you, it’s a call to action directed to the people you are wanting to reach – it motivates them to collaborate with you in ways that will help all of you to achieve something that’s really valuable.* (“Crafting,” para. 2)

In inclusive research, support is required to first collect their stories, and sometimes these exist on their own, simply as previously untold stories of particular experiences of the world. Using methods based on grounded theory research methodology, however, it is possible to discern the repeating, overlapping parts (themes) to find what Hagel (2013) terms “a persistent narrative” (para. 1–3). Research

methodology is training local self-advocates have not had access to, although there have been many successful and varied inclusive research projects around the world (e.g., Johnson, 2010; Roets, 2009; Vandekinderen, Roets, Roose, & Hove, 2012; Walmsley & Johnson, 2003; Worrell, 1988; Young & McDonagh, 2012). Such initiatives require flexible, interested allies with some knowledge of context and history, who are in relationship deeply enough to be trusted, and a belief that people with ID need not be limited by a capacity for only what is concrete, but can deal with abstract thought.

Scholarly Discussion of the Implications of the Integrated Findings

Culturally, our growing interest and appreciation for diversity in the ways that other cultures lead creates new openings for understanding differences and rethinking assumptions about people with intellectual disabilities as leaders. Self-advocates often refer to “disability world”—a kind of static parallel existence to the real world of relationships and change, based on a medical model, an idea that is opposite to a social constructionist conceptualization of education and co-learning, which imagines dynamic, evolving interdependent and global connections. It is a useful paradigm to bring to self-advocate leadership, as “what we take to be knowledge about the world thus expands exponentially, while simultaneously undermining the credibility and often the utility of any taken-for-granted world” (Dragonas, Gergen, McNamee, & Tseliou, 2015, p. xii).

Leadership as a concept within the community of people with ID has been a difficult area to pin down and study within traditional research paradigms because it is constantly on the move, dependent on relations and context. This also makes the constructionist stance a useful, potentially generative one. Gergen (2015b) states,

> *A constructionist orientation replaces the conservative leaning of the empiricist orientation with a contextual vision. Rather than seeking irrefutable propositions, the constructionist understands and appreciates the possibilities of multiple understandings, depending on time, culture, and circumstance. The greater the number of perspectives that can be assembled in a situation, the greater the range of possible actions. Multiplicity and pragmatic potential are allied.* (p. 3)

Gergen (2015b) continues on to say that "knowledge making should not be cumulative, but continuous" (p. 4) and useful to those involved, which he has characterized elsewhere as "*reflective pragmatism"* (p. 4).

There is a larger body of research on how self-advocates can be included than there has ever been before, and given the United Nations (2006) *Convention on the Rights of Persons with Disabilities* AND the increasing desire of communities to include all members, it would be good to have some form to gather and disseminate this information. Critical disability studies as it involves people with ID is one way to do this. One of the most significant events of my own growth as an ally was the discovery of Griet Roets's (2009) "Unravelling Mr President's nomad lands: travelling to interdisciplinary frontiers of knowledge in disability studies," and I know from using it as an assigned reading with my students that it has been transformational for them as well. While it was one of the first such documents for me, it was not the first document in critical disability studies and it has certainly not been the last. This has become a lively, engaged field of growing knowledge and if we can create bridges from critical disability studies to support organizations and self-advocates and the groups they are part of, there could be a significant shift in the conversation about inclusion.

In their initial input into the research project, self-advocates defined leadership as something interwoven through their lives, the groups they were part of and the communities where they lived and worked. It was relational and contextual. This sense of leadership as a complex issue is reflected in the small body of qualitative research about leadership functions in the lives of people with ID (Goodley, 2000; Roets, 2009; Simplican, 2015).

Social constructionist theory and methodologies also demonstrate the capacity to engage in new meaning-making with all parties. While the social model of disability has existed for some time, social constructionism gives us ways to create a more desirable, inclusive future by creating more welcoming and inclusive places to ask questions of each other and share our stories. Indeed, this research might be said to end

where it began, with Arnold's voice: "I know you think you've heard it all before but this is a story everyone wants to hear."

In some part of me, as I have worked on this, I have imagined creating something with enough evidence and instruction so that everyone can just be together in reciprocally enriching ways, moving forward into community. I wanted handouts that I could give people that would convey how everyone could be included and what they might have in common and how they might talk together. It seemed to me there was a need for such tools. While some practical tools are in these pages, the research has also brought me to a new place of letting go of the need to make things work, while increasing the sense of commitment and clarifying the need for values-based leadership in allies. The people who want things to work will seize the tools, as they have seized previous iterations of other tools. The others will ignore them as they have ignored previous tools. I was struck by this sentence:

> *Often in community engagement work, what people tend to listen for and work to develop are the harmonious sounds of operationalized citizenship (Taliaferro, Casstevens, & Gunby, 2013); a community that is inclusive and equitable and where its people feel that they are valued and have not only equal rights, responsibilities, obligations to society, and privileges of membership, but also equal capacity to activate those rights, fulfill their responsibilities, meet their obligations and to be advantaged by their privileges. I realize at the end of this project that the primary outcome of this work is not to move towards harmony. Rather, the methods I have developed are better conceptualized as understanding the community harmonics.* (Hooker, 2014, p. 349)

The lack of research and resources about leadership in the lives, groups and communities of people with intellectual disabilities is in contrast to their abundance of authentic leadership of all kinds, in all areas of life. The lack of an accessible body of research and materials to support a belief in self-advocate leadership and the growing of leadership skills and connections makes a consistent, appreciative, future-forming approach more challenging. The information gathered in this dissertation is an attempt to add to the body of this knowledge.

References

Ashby, C., Jung, E., Woodfield, C., Vroman, K., & Orsati, F. (2015). 'Wishing to go it alone': The complicated interplay of independence, interdependence and agency. *Disability & Society, 30*(10), 1474–1489. doi:10.1080/09687599.2015.1108901

Berghs, M., Atkin, K., Graham, H., Hatton, C., & Thomas, C. (2016). Implications for public health research of models and theories of disability: A scoping study and evidence synthesis. NHS, National Institute for Health Research. *Public Health Research, 4,* 8.

Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 27*(1), 3–12. doi:10.1111/jar.12083

Briton, D. (1996). The modern practice of adult education: A postmodern critique. Albany, NY: State University of New York Press.

Crunden, E. A. (2017, June 22). *Wheelchair users dragged away from McConnell's office for protesting health care bill.* Retrieved from https://thinkprogress.org/wheelchair-protesters-arrested-ahca-dc-c7ecf4c94f59

Dragonas T., Gergen, K. J., McNamee, S., & Tseliou, E. (Eds.). (2015). *Education as social construction: Contributions to theory, research and practice*. Chagrin Falls, OH: Taos Institute/WorldShare Books.

Duffy, S. (2016, August 3). *Confusopoly – lessons for social change.* Retrieved from http://simonduffy.blogspot.ca/2016/08/confusopoly-lessons-for-social-change.html

Etmanski, A. (2015, September). *Collective impact summit: Day 3 highlights.* Retrieved from http://tamarackcci.ca/files/ci_day_3.pdf

Fraser, N., & Gordon, L. (1994). A genealogy of dependency: Tracing a keyword of the U.S. welfare state. *Signs, 19*(2), 309–336.

Gerber, D. (2017). Disability scholars as world disrupters and worldmakers. *DSQ: Disability Studies Quarterly, 31*(1). doi:10.18061/dsq.v37i1.5441

Gergen, K. J. (2009). *An invitation to social construction* [Electronic version]. Retrieved from https://www.amazon.ca/Invitation-Social-Construction-Kenneth-Gergen/dp/1412923018

Gergen, K. J. (2015a). From mirroring to world-making: Research as future forming. *Journal for the Theory of Social Behaviour*, *45*(3), 287–310. Retrieved from http://works.swarthmore.edu/cgi/viewcontent.cgi?article=1796&context=fac-psychology

Gergen, K. J. (2015b). From propositions to practice pedagogy for life as process. In T. Dragonas, K. J. Gergen, S. McNamee, & E. Tseliou (Eds.), *Education as social construction: Contributions to theory, research and practice* (pp. 49–61). Chagrin Falls, OH: Taos Institute/WorldShare Books.

Goble, C. (1999). “Like the secret service isn't it.” People with learning difficulties, Perceptions of staff and services: Mystification and disempowerment. *Disability & Society*, *14*(4), 449–461. doi:10.1080/09687599926064

Goode, B. (n.d.). Seniors ambassador article “becoming a senior ambassador.” Retrieved from http://selfadvocatenet.com/seniors-ambassador-article-becoming-a-senior-ambassador/

Goodley, D. (1997). Locating self-advocacy in models of disability: Understanding disability in the support of self-advocates with learning difficulties. *Disability & Society, 12*(3), 367–379. doi:10.1080/09687599727227

Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties: The politics of resilience.* Berkshire, England: Open University Press.

Goodley, D. (2005). Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities, 9,* 333–343. doi:10.1177/1744629505059267

Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society, 28*(5), 631–644. doi:10.1080/09687599.2012.717884

Goodley, D. (2016). *Disability studies: An interdisciplinary introduction* [Electronic version]. Retrieved from https://www.amazon.ca/Disability-Studies-Interdisciplinary-Introduction-Goodley/dp/1847875580

Hagel, J. (2011, May). *The pull of narrative – in search of persistent context.* Retrieved from http://edgeperspectives.typepad.com/edge_perspectives/2011/05/the-pull-of-narrative-in-search-of-persistent-context.html

Hagel, J. (2013, October 21). Narrative and passion [Web log post]. Retrieved from http://edgeperspectives.typepad.com/edge_perspectives/2013/10/narrative-and-passion.html

Hooker, D. A. (2014). *Performing greensboro: Using Foucaldian analysis to deconstruct 'trouble in mind' and generate alternative community narratives*. Retrieved from https://pure.uvt.nl/portal/files/4072335/Hooker_Performing_15_09_2014.pdf

hooks, b. (1990). *Yearning: Race, gender and politics*. New York, NY: South End Press.

Horwood, W. (1987). *Skallagrigg*. New York, NY: Viking.

Johannes, A. (2011, December 9). *Leadership and intellectual disability: A grounded theory exploration of stories of self-advocate leaders*. Unpublished document.

Johnson, R. (1994). *Lost in a desert world: An autobiography* [Electronic version]. Retrieved from https://www.amazon.com/Lost-Desert-World-Roland-Johnson-ebook/dp/B00HGK10ZQ

Johnson, K. W. (2010). *People with intellectual disabilities: Towards a good life?* Bristol, United Kingdom: Policy Press.

Lakoff, G., & Johnsen, M. (2003). *Metaphors we live by* [Electronic version] (2nd ed.). Retrieved from http://shu.bg/tadmin/upload/storage/161.pdf

Luetke-Stahlman, B. (1997). *Preparation of leadership personnel: Combined deaf education/learning disabilities*. Retrieved from http://files.eric.ed.gov /fulltext/ED422672.pdf

Macdonald, N. (2017, March 13). How Indigenous people are rebranding Canada 150. *Maclean's.* Retrieved from http://www.macleans.ca/news/canada/how-indigenous-people-are-rebranding-canada-150/

McCallum, D. (2001). *The need to know: Administrative review of Woodlands School.* Retrieved from http://www.inclusionbc.org/resources/need-know-administrative-review-woodlands-school

McKnight, J. (1995). *The careless society: Community and its counterfeits.* New York, NY: Basic Books.

McNamee, S. (2014). Research as relational practice. In G. Simon, & A. Chard (Eds.), *Systemic inquiry: Innovations in reflexive practice research* (pp. 74–94). Farnhill, United Kingdom: Everything is Connected Press.

Meekosha, H., & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies? *Australian Journal of Human Rights, 15*(1), 47–75.

Pallotta, D. (2009, June 22). *"Efficiency" measures miss the point.* Retrieved from https://hbr.org/2009/06/efficiency-measures-miss-the-p/

Pallotta, D. (2010, November). Our ineffectiveness at measuring effectiveness*. Harvard Business Review.* Retrieved from http://blogs.hbr.org/2010/11/our-ineffectiveness-at-measuri/

People First of Canada. (1993). *Our stories: The stories of some of the leaders of People First in Canada and a workbook for people first member to tell their own stories*. Unpublished document.

Pierre, J. S., & Peers, D. (2016). Telling ourselves sideways, crooked and crip: An introduction. *Canadian Journal of Disability Studies, 5*(3), 1–12. doi:10.15353/cjds.v5i3.293

Plutarch. (75 A.C.E.). *Theseus* (J. D. Trans., Ed.). Retrieved from http://classics.mit.edu/Plutarch/theseus.html

Point, N. R. (2011). *Reanimating storywork: Indigenous elders' reflections on leadership*. Retrieved from http://summit.sfu.ca/item/10342

Roets, G. (2009). Unravelling Mr President's nomad lands: Travelling to interdisciplinary frontiers of knowledge in disability studies. *Disability & Society, 24*(6), 689–701. doi:10.1080/09687590903160142

Roman, L. G. (2009). The unruly salon: Unfasten your seatbelts, take no prisoners, make no apologies! *International Journal of Qualitative Studies in Education, 22*(1), 1–16. doi:10.1080/09518390802581901

Roman, L. G., Brown, S., Nobel, S., Wainer, R., & Young, A. E. (2009). No time for nostalgia!: Asylum-making, medicalized colonialism in British Columbia (1859–97) and artistic praxis for social transformation. *International Journal of Qualitative Studies in Education, 22*(1), 17–63. doi:10.1080/09518390802581919

Simplican, S. C. (2015). *The capacity contract: Intellectual disability and the question of citizenship*. Minneapolis, MN: University of Minnesota Press.

Smith, J. D., & Wehmeyer, M. L. (2012). *Good blood, bad blood: Science, nature, and the myth of the Kallikaks* [Electronic version]. Retrieved from https://www.amazon.ca/Good-Blood-Bad-Science-Kallikaks/dp/1937604039

Suzuki, D. (2017, February 2). Indigenous people are fighting for us all [Web log post]. *Science Matters.* Retrieved from http://www.davidsuzuki.org/blogs/science-matters/2017/02/indigenous-people-are-fighting-for-us-all/

Titchkosky, T. (2011). *The question of access: Disability, space, meaning*. Toronto, Canada: University of Toronto Press.

Trent, J. (2017). *Inventing the feeble mind: A history of intellectual disability in the United States* [Electronic version] (2nd ed.). Retrieved from https://www.amazon.com/Inventing-Feeble-Mind-Retardation-Medicine/dp/0520203577

Truth and Reconciliation Commission of Canada. (2015). *Truth and Reconciliation Commission of Canada.* Retrieved from http://www.trc.ca/websites /trcinstitution/index.php?p=3

United Nations. (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-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

Vandekinderen, C., Roets, G., Roose, R., & Hove, G. V. (2012). Rediscovering recovery: Reconceptualizing underlying assumptions of citizenship and interrelated notions of care and support. *The Scientific World Journal, 2012*. doi:10.1100/2012 /496579

Walmsley, J. (2004). Inclusive learning disability research: The (nondisabled) researcher's role. *British Journal of Learning Disabilities, 32*(2), 65–71. doi:10.1111/j.1468-3156.2004.00281.x

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. Philadelphia, PA: Jessica Kingsley.

Worrell, B. (1988). *Advice for advisors: People first*. Downsview, Canada: G Allan Roeher Inst Kinsman.

Young, A. E. (2006). *Elders' teachings on indigenous leadership: Leadership is a gift* (Master’s thesis, University of British Columbia). Retrieved from https://open.library.ubc.ca/cIRcle/collections/ubctheses/831/items/1.0064638

Young, P., & McDonagh, P. (2012). In A. Johannes, S. Stanfield, J. Reynolds, & P. McDonagh (Eds.), *From institutions to individuals* (pp. 41–48). Vancouver, Canada: Spectrum Press.

Appendices

Appendix A: Example, Graphic Facilitation

Johannes, Aaron. "How Collaborative Research Works."

Appendix B: Participant Recruitment/Information Letter

Initial "Plain Language" Letter to Prospective Participants [the basis of a personalized script if the person prefers to be contacted by phone or in person]

Dear participant:

Thanks for considering supporting my research which looks at stories of how people with disabilities have been successful leaders in their lives, groups they are part of and in their communities. My project is tentatively called: *"What Works: Self-Advocate Leadership in their Lives, Groups they are part of and in their Communities*." It is part of my research for my Ph.D. from the Taos Institute, in partnership with the Free University of Brussels. When it is done my research will be available for others to read and look at, and I will also create a plain language version available to you and others who are interested in self-advocate leadership.

I will be meeting with small focus groups of people with intellectual disabilities who, for the purposes of this study, self-identify as having or having had a disability because of diagnoses they have experienced. I am particularly interested in meeting with people with a range of disabilities, communication methods, over a range of ages.

I will meet with focus groups for up to four hours at a time to talk about leadership in their lives, groups and communities. At the request of my self-advocate advisors, who want this to be a learning opportunity for everyone, we will also look at current research about leadership and intellectual disability.

Discussions about your experiences as leaders will then be co-facilitated by experienced self-advocate leaders, and recorded as graphics by a self-advocate graphic recorder, supported by me as necessary. Some discussions will be about specific projects that people have been part of.

Information from the focus groups will be written up and looked at later to look for things in common that worked well to support leadership roles, which I will then write about. My intention is to create a body of work to support increased leadership of people with intellectual disabilities. In each gathering I hope that people will learn more about their own leadership capacity and potential from the research and from each other in the meetings, and that my work will also help people in the future.

Although all the information we discuss will be confidential, if anything comes up that is against the law or for some other reason requires reporting, I will need to go the appropriate authority.

There will be no costs to you or other participants. Please understand that you do not need to accept this request for any reason. Nothing will be affected by your decision to participate or not.

If you're interested in seeing the research so far, check out: http://imagineacircle.com/leadership-research-update/ If you have any questions, please contact me by phone at [telephone number] or by email at [email@...org]. If you wanted to contact my research supervisor, Dr. Ginny Belden-Charles, her contact information is phone [phone number] or email [email@...net.]

Thanks in advance for considering this request!

Yours truly,
Aaron Johannes

Appendix C: INFORMED CONSENT

Agreement to participate in "What Works: Self-Advocate Leadership in their Lives, Groups they are part of and in their Communities."

Consent Form

"What Works: Self-Advocate Leadership in their Lives, Groups they are part of and in their Communities."

Principal Investigator: (principal investigator is the person in charge of the project): Aaron Johannes, M.A.I.S., Phone: [phone number] or [email@gmail.com]
If you need help understanding what is written on this form, you can ask for help from the person who gave you this form, from Aaron, or Aaron can put you in touch with one of the self-advocate co-researchers.
This research is part of a dissertation for a Ph.D. degree. The dissertation will be a public document. This form will let you know how your information will be used. You have a right to confidentiality when you share information.

Purpose: Why is this study being done?

The reason for this research is to know what people, supports or ideas best support people with intellectual disabilities as leaders. You have been asked to participate because you are considered to be someone who has acted as a leader or participated in groups of leaders.

Study Procedures: What is involved?

If you will participate, you will be part of a small focus group who will meet for no more than four hours to discuss the idea of leadership and then talk about examples from your lives in which you have felt successful as a leaders in various ways. While people are talking we will be graphically recording the conversation on big sheets of paper with markers, to make sure that we are clear about what we are discussing. The whole discussion will be audio recorded and then written up later and those notes and the drawings, will allow me to find some common ideas about what has been helpful to people. There is a chance that I will call or contact you later for further clarification of some of these ideas. Any other conversation will be less than half an hour. Your total involvement will take no more than four and a half hours.

Confidentiality

Your personal information will be kept confidential in all of the records of the researcher. For the purposes of my work, names of participants will be stripped from all the recorded information as soon as possible. Recordings of your participation will not be shared with anybody but me. All of the records from this study will be locked in a safe place or protected by passwords on a data storage drive. You will receive a copy of the final paper and a plain language and graphics version of the paper that you can share and use. These documents will be kept here:
http://imagineacircle.com/leadership-research-update/

We will encourage focus group participants not to share the information from the discussion with anyone else. However, we can not control or make sure that the discussions will not be shared outside the group.

What are the risks of participating?

For some people, talking about leadership and disability can bring up sad or painful feelings and memories. Some people find it helpful to talk about these things and my hope is that these conversations will lead to immediate learning for you about how to lead more successfully. It is okay to stop your participation at any time and not be part of the research. It is also possible to talk privately with someone else, including a therapist or a counsellor. Please let me know if I can help with a list of options if you feel the need to follow up after our conversation.

Are there any benefits of (good things about) participating?

Being part of this research study is a chance to think about what you've accomplished with others, and perhaps to get some ideas about how you might participate as a leader in other ways. You will have your voice heard about leadership and disability, and connect with other people who share your experiences. You will be provided with the results of the study in a plain language format.

Remuneration/Compensation – Is there pay involved?

No.

For More Information

You can check out the research so far on this site: http://imagineacircle.com/leadership-research-update/ You can contact the people named above if you have any questions about this study or your participation. You can contact me by phone at [phone number] or by email at [email@gmail.com]. If you wanted to contact my research supervisor, Dr. Ginny Belden-Charles, about any concerns, her contact information is phone [phone number] or email [email@...net] or you may contact the Douglas College Research Board Chair, Dr. Edrie Sobstyl, [email@...ca].

Consent

Your participation in the study is voluntary. You can refuse to participate (say no) or withdrawal from the study (stop your participation) at any time no matter what. **Your signature below says** that you have received a copy of this consent form for your own records.

Your signature says that you consent to participate in this study.

Signature:

Printed Name:

Date:

Appendix D: Ethics Approval

OUGLASCOLLEGE
O Box 2503 New Westminster BC
anada V3L 5B2
ew Westminster and Coquitlam
ouglascollege.ca
04 527 5400

REB CERTIFICATE OF APPROVAL	CERTIFICATE NUMBER: FE16.01a

Name, address, and email of principal researcher: Aaron Johannes, 1424 Seventh Ave. New Westminster BC; johannesa@douglascollege.ca

Name of Co-investigator(s): NA

Project Title: What Works: Self Advocate Leadership in their lives, groups they are part of and in their communities

The Douglas College Research Ethics Board has reviewed your application to conduct research involving human participants. We are pleased to report that your project has been APPROVED.

REB approval for your project expires on the date shown at the bottom of this letter. You must request an extension of the project if it is not concluded by this date. Following the conclusion of the project, you have thirty (30) days to submit a final report to the REB.

You must notify the REB of any changes in the study. Any unanticipated issue that increases the level of risk to participants or has other ethical implications should be reported to the REB without delay. Major changes will require the submission of a revised request for ethical approval of the research project.

Any adverse events (research-related injuries, distress, or other harms) must be reported to the REB as soon as is practically possible.

The REB may ask to review any part of the research while it is being conducted, or after the completion of the project.

Please print a copy of this letter and retain it with your study records.

If you have any questions or need further assistance, please contact the Chair of the REB, Dr. Edrie Sobstyl: sobstyle@douglascollege.ca.

Good luck with your research.

Signature of REB Chair:

Date of letter: 2nd May, 2016
Expiration date for approval: 2nd May 2017

Appendix E: Documents of the Lower Mainland Community-Based Services Society

Documents of Lower Mainland Community-Based Services Society.

1. Certification of Incorporation, 21 July 1988, including
    a. Constitution and By-Laws, July 6, 1988
2. Proposal Letter to develop two semi-independent living programs, Sept 19, 1989 (recipient redacted by posAbilities), including
    a. Semi-Independent Adult Residence, Women
    b. Semi-Independent Adult Residence, Men
    c. "Admission Guidelines for Specialized Adult Residence"
    d. "Specialized Adult Residential Program" program description
3. "History of Lower Mainland Community-Based Services Society," circa 1995
4. "Policy and Procedures," manual, Sept 1995
5. "Biographies, Board of Directors, 1995-1996, including, "Nominees – Running for Director"
6. "Residential Programs," which is an update on all the homes, programs and people served and might have been part of an election package
7. "Semi-Independent Adult Residence" (n.d., n.p.) program description
8. "Specialized Adult Residential Program" program description
9. "Admission Guidelines for Specialized Adult Residence"
10. Executive Director's Report, June 1996, Susan Reimer
11. President's Report, June 1996, Barb Goode
12. Ridgeview Heights, a progress report on a new housing development, June 3, 1996
13. "Board Member Orientation, Draft"

Appendix F: Barb Goode's Story of the Eve Case

Barb Goode's Eve Case story, transcribed and supported by Sandra Polushin, September 30, 2016.

Sunday October, 23rd, 2016. It will be the 30th Anniversary of the "Eve Case." The case was about sterilization of a woman with a disability.

Her mother was worried about her having children because she saw her daughter holding hands with a man. It went to a smaller court in PEI at the beginning.

I feel very strongly that we can't forget about it and Eve's Case.

Question: How did you/we get involved with Eve's case?

I was on a board of the Canadian Association for the Mentally Retarded. It is called Canadian Association for Community Living now. **I was on another committee, called the Consumer Advisory Committee**.

Someone brought up Eve's story to the to the board. Lots of parents were on the board at that time. They felt one way about it, and we felt another.

As part the Consumer Advisory Committee, Harold Barnes, Dulcie McCallum and Peter Park were also involved. Other members were involved from BC, Alberta, and Toronto.

As a committee, we felt someone needed to do or say something. We asked David, one of the board members and parent of a child with a disability if he could help us. He agreed.

David Vickers and Orville Endicott and others were our lawyers. Dulcie McCallum was working with Dave Vickers at the time.

I felt it was important to have a woman helping us. The board of CAMR/CACL had members who didn't know what to think.

As a committee, Harold Barnes and Peter Park worked on Eve's case with long day's with our staff and lawyer's.

(Some of Harold's memories) We would have a Consumer Advisory Committee meeting or a "Canadian Association for Community Living" board meeting. Sometimes we met in different places like Victoria. Sometime when CACL was having their Annual General Meeting's, we would have a meeting.

Most meetings started at 9 o'clock. In the morning, Toronto time, we would go til after 8 at night. We talked between meetings also.

It was very worthwhile.

Question: Why was it important for you and your committee members to speak out?

As a committee, we thought no one should be sterilized without their say (consent). We felt very strongly about it.

Our lawyers were very supportive and all 9 judges agreed with our committee.

The 'Eve Case" was important because sometimes people are still being sterilized without their consent.

*** (Barb wants to ask Harold for permission before including the next two sentences)

Before I forget, I am sorry I didn't say I always thought being sterilized was a women's issue til Harold told us (our committee) that he was sterilized without his consent.

He reminded the committee that men can get sterilized also. He was told he couldn't leave where he was living until he was sterilized. He was living in an institution at the time.

Question: What were the results of the work of your committee

It took a long time to take it to court. Most of the members from the Consumer Advisory Committee were on the committee a long time.

I was very happy to be able to be part of Her story/History. It went to the Highest court in Canada. The Supreme Court of Canada in Ottawa, Ontario.

I was very thrilled when we won the case. A few of us were in the court room when the judges decided.

Do you have any last thoughts?

As far as I know, "Eve" doesn't know how famous she is. "Eve" was 24 at the time. (Not her real name). She doesn't know how important she is to everyone.

It important to remember that people don't get sterilized without say (consent).

If it has to happen for any reason, it should be for medical issues only.

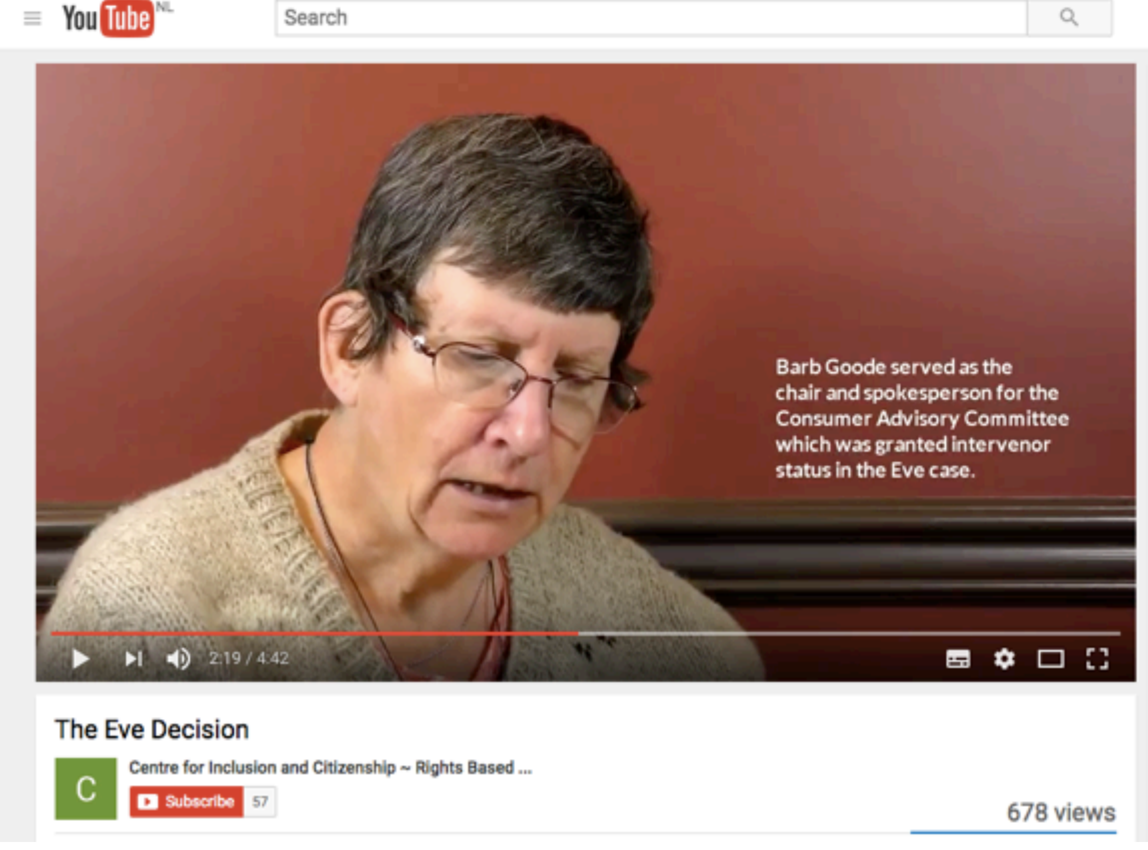
If we do need to have it done:

1. ask us
2. explain it in plain language in a way we understand.

This story became a video on YouTube:
https://www.youtube.com/watch?v=MqFmn6hi6V4

It was also used as part of the University of British Columbia's Centre for Inclusion and Citizenship's new site for resources on the Eve case, "The Eve Decision, 1986

October 23, 2016 Marks the 30th Anniversary of 'The Eve Decision'"
http://cic.arts.ubc.ca/the-eve-decision-1986/



Appendix G: Teaching Video

Another video in which Barb and Aaron talk about the Eve case and their research on leadership is currently in the process of being edited

In production.

Appendix H: Agenda for "Community Conversation" on Leadership

Appendix I: Handout: Planning for Leadership

Appendix J: Social Media Research Dissemination Sites

These distributed information about the research project to the wider provincial self-advocate community selfadvocatenet.com: Posted September 10, 2015. Workshop May 29, 2015. What Works: Self-Advocates as Leaders in their Lives, Groups, and Communities from Aaron Johannes http://selfadvocatenet.com/what-works-for-self-advocate-leaders-reflecting-on-our-workshop-at-inclusion-b-c/

UBC Centre for Inclusion and Citizenship: Posted October, 2016. It was also used as part of the University of British Columbia's Centre for Inclusion and Citizenship's new site for resources on the Eve case, "The Eve Decision, 1986

October 23, 2016 Marks the 30th Anniversary of 'The Eve Decision'"
http://cic.arts.ubc.ca/the-eve-decision-1986/

Slideshare

December 2013: https://www.slideshare.net/aaronjohannes2/leadership-and-people-with-disabilities-a-collaborative-study-using-graphic-facilitation

May 2015: https://www.slideshare.net/aaronjohannes2/reflecting-onwhat-works-self-advocates-as-leaders-in-their-lives-groups-and-communities

September 2016: https://www.slideshare.net/aaronjohannes2/what-works-for-self-advocate-leaders-research-update

Blog

https://imagineacircle.com/leadership-research-update/

Appendix K: Graphic Explanation and Update on our Work for Conferences and Events (Modified)

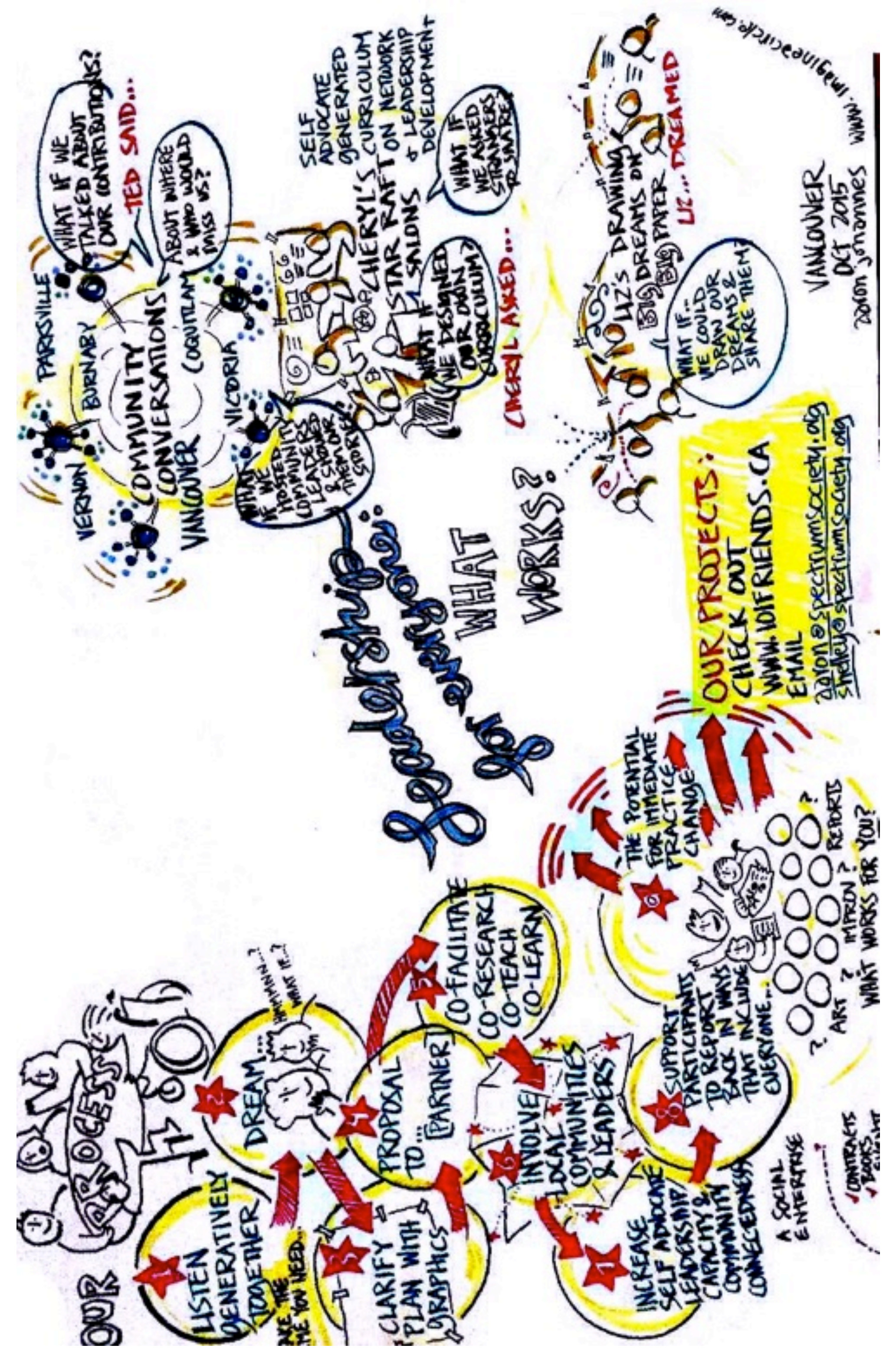


Figure: Draft graphic of dissertation