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Cultivating Disability Leadership: Implementing a Methodology of Access to Transform Community-based Learning

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Abstract

In this paper, we describe a methodology of access developed and applied during a three-year project in the Niagara region focused on cultivating the next generation of disability leaders. We describe the theoretical approach to the project and highlight the significance of doing this work in Niagara. A literature review of adult, transformative, and community-based learning scholarship revealed that little research or writing has focused on describing a thorough approach to access in transformative projects in community-based settings. Writing with two participants from the study, we elaborate on the five dimensions of our approach: 1) funding; 2) local and focused; 3) intimate, relational, and interdependent; 4) curating access, and 5) welcoming disruption. We also describe the tensions in taking on this work. We conclude with an invitation to scholars, community groups, and organizations to consider integrating our methodology in their next research project.

Keywords

Access, Adult Education, Community-Based Learning, Niagara, Disability Justice

Introduction

Disability Studies (DS) scholarship continues to assert itself within the post-secondary terrain, even though significant political and financial constraints exist within the sector (Cushing, 2009). It is important to continue to focus on efforts to maintain and grow DS in academia. However, we also believe that DS education needs to extend to the community where disabled people and the disability rights movement were instrumental in its early beginnings.

The purpose of this paper is to detail and discuss Next to Lead¹, a transformative education project in a community-based setting that focused on teaching DS, leadership, and community activism to a group of 25 young disabled adults in the Niagara region of Ontario, Canada. In consultation with the Niagara Centre for Independent Living – the only consumer-run organization in the region – we saw the need for Disability Studies-centric education as there were little other positive disability spaces.

Over the last decade or so, disability rights organizations, leaders in the community, and scholars have identified the need to develop and support the next generation of disabled leaders (Hutchison et al, 2007; Lord, 2010). Strong leaders in the next generation will mean that past gains such as Direct Funding, inclusion of disability as a protected category in the Charter of Rights and Freedoms, the establishment of the Accessibility for Ontarians with Disabilities Act (AODA), and many other political, cultural, and artistic achievements in the community, may be maintained and advanced. Kelly and Carson (2012) and Kelly (2013) argue that disability movements in Canada have struggled to attract the participation of young people, but as they also articulate, young disabled people are participating in radical political activism, often just outside

¹ Next to Lead grew out of an earlier project, “Our Histories: Building leadership and engagement in the disability community - Lessons learnt from Toronto’s disability leaders”, which focused on collecting first-generation disability leaders’ oral histories in Toronto.

of the non-profit sector. We intended to bridge this gap by bringing together young disabled people within the non-profit sector and named the project Next to Lead.

Theoretically, the project was guided by a disability justice framework, which centers the collective and entwined multiple systemic oppressions experienced by disabled people (Berne, 2015; Sins Invalid, 2012). This includes the oppression of mad people and the interrogation of the sanism promoted by the psy-disciplines (LeFrançois et al., 2013; McAvoy, 2014). Disability justice also embraces a commitment to collective access, interdependence, cross-disability and cross-movement solidarity, led by those most impacted within these systems (Berne, 2015; Mingus, 2010; Sin Invalid, 2012). In this paper, we illustrate our understanding of disability justice in the development and implementation of the core approach within the project that we call a methodology of access. This methodology has five dimensions. They are funded and resourced, local and focused, intimate, relational and interdependent, accessible and long-form, and spontaneous and reflective. This methodology builds on the work of Bonnie Burstow (2002, 2003) and other scholars in adult, community, and transformative education.

Literature Review: Access and Adult, Community, and Transformative Education

There is significant discussion of access within adult and transformative education literature (Clark, 2006; Procknow, 2017; Rocco & Delango, 2011). Much of the focus in this area is on formal education settings (Castrodale, 2015, 2017; Dolmage, 2017; Ross-Gordon, 2018), including access in higher or further education (Larragy, 2004; Landmark et al., 2010; Landry & Church, 2016; Price, 2011; Snyder et al., 2019; Rothman et al., 2008; Titchkosky, 2011), continuing education (Panitch, 1988; Uditsky & Hughson, 2006), or vocational training (Lewis et al., 2011a, 2011b). While the strategies to produce access discussed in this literature

are transferable to non-academic or community-based settings, but there are also unique elements to teaching in the community that require their own considerations. These include elements such as the length of a community project, the distances individuals may have to travel, the lack of resources or other supports that a formal education setting offers, and the absence of formal evaluation processes.

Discussion of access as a methodology in community-based projects has been very limited (Burstow, 2002). And while there are elements in adult, community, and transformative education that speak to creating accessible spaces, such as descriptions of sanctuary spaces (Lange, 2009), the importance of extended time in community settings (Maton, 2008), flexibility (Clover & Craig, 2009), the use of plain language (Gorman, 2000), of providing food (Clover & Craig, 2009), and covering the cost of transportation (Hoffman, 2016), this is not stated within a larger framework of reconfiguring learning environments to undo their inherent ableist and sanist dimensions. We would characterize many of these specific changes as accommodations – individualistic changes that allow for only some individuals to participate in learning environments. Burstow (2002) on the other hand, outlines her approach to access for psychiatric consumer/survivors. She centers the learner and considers their personal histories – of trauma and violence, of distrust of authority, their fear of others, their low self-esteem. She makes space for the effects of psychiatric medication on eyesight, attention span, and memory. She acknowledges the importance of validating those who hear voices, who live between realities, of spending time listening to stories that have no connection to the project or the topic at hand. Burstow (2002) describes the significance of large print materials for those with low or blurred vision, the importance of regular breaks, food, safe space, and relaxed pacing. Her approach is

significant because she addresses the material and immaterial qualities of access amongst psychiatric/consumer/survivors.

Burstow's (2002) approach provides a foundation to think about access for diverse learners. We built on this strong foundation and have articulated our approach as a methodology of access. Our additions include the importance of funding, of the necessity of being local and focused, of generating intimacy among the group and with the team, of curating access, and welcoming disruption. By implementing a methodology of access – making the project as anti-ableist and anti-sanist as possible, we contend that participants began to see how things could be different – and thus imagine how they might contribute to this change-making. To ensure our success, we learned about the community we would be working in. In the next section, we outline this context and discuss the Niagara region, its governmental structure, demography, and overall understand of, and approach to disability.

Niagara Region – Context for the Next to Lead Project

The region of Niagara is located in Southern Ontario and covers 1854.25 square kilometers (Niagara Region, Area Municipalities, 2018) with 447,888 residents (Statistics Canada, Census Report, 2016). The region is divided into 12 individual municipalities with more than half the regional population concentrated in three municipalities (Contact Niagara, 2004; Statistics Canada, 2016). These three municipalities (St. Catharines, Niagara Falls, and Welland) cover a relatively small geographic area within the region, and the remaining residents are dispersed across the remaining municipalities (Niagara Region, 2017).

Niagara also has a two-tier government structure. Area municipalities have some individual level of governance but are also governed by a regional council that oversees activities

for all 12 municipalities in Niagara. This governmental structure makes coordinating and accessing services in the region challenging (Contact Niagara, 2004). In addition, the majority of agencies providing community, health, and social services to residents of Niagara have their main offices located in the three most densely populated municipalities in the region (Contact Niagara, 2004). This organizational structure means that many disabled people in the region have to travel long distances to access health care services and supports they need in an area where the infrastructure for transportation is limited or non-existent.

Historically, two regional service providers informed the local conceptualizations of childhood and youth disability. The first is the hospital-based children's rehabilitation project, which grew from specialized services for children and youth with physical disabilities in the 1950s by a local women's charity (Maycourt Club). The program originally ran out of a local church, but after seeing a gap in therapy services for local children and wishing to fill this gap, the program moved to the St. Catharines General Hospital. This hospital-based approach to service helped reinforce the common view of disability as a medical problem in need of fixing (Oliver, 1990), thus setting the foundation for how local disabled children's health/rehabilitation services would be managed going forward.

The second regional provider to influence conceptions of disability was the Bethesda agency. This was a local Christian based organization with a long history of providing charitable services for children and youth with developmental disabilities (Thiessen & Steiner, 2017). Bethesda (formerly Bethesda Mental Hospital), has been a residential home for those with "mental illness" and for individuals labelled with developmental disabilities. Religion-based organizations run on a charity model, and while these organization provided care, they were also spaces that restricted or discouraged discussions on certain topics (sex, sexuality, etc.). Charity-

based models of disability also perpetuate the notion of disability as tragic and pitiable.

Therefore, we suggest that dominant medical/charity-based models of disability reinforced understandings of disability as individual and tragic, leaving little room for competing conceptualizations of disability in the region.

Demographically, the entire region has a population with a mean age slighter older (46 years) than the provincial average of 41 years of age (Niagara Region, Population and Demographics, 2018; Statistics Canada, 2016). In addition, the senior population (those over 65) in the region is higher than the provincial average and, in some municipalities, seniors make up 24-30% of the total population (Statistics Canada, 2016). Like the trend for most ‘rural’ communities, the youth population (20%) in Niagara is declining, as youth migrate to urban centers to pursue higher education and employment (Niagara Region, Population and Demographics, 2018; Moazzami, 2014). However, from speaking with participants in the project, only a small handful desired to leave Niagara, while many others contemplated leaving but abandoned such plans because they relied on friends and family too much to move away from them. This further underscore the importance of positive disability spaces in rural and remote regions where young disabled people may be unlikely to leave and join movements in urban spaces.

Visible minorities² in Niagara constitute only 6.3% of the population compared to 22.8% in Ontario (Statistics Canada, 2016). In the smaller local municipalities this percentage is even less; for instance, in West Lincoln visible minorities make up only 1.4% of the population (Niagara Region, Population and Demographics, 2018.). St. Catharines, the largest municipality,

² “Visible minorities are defined as persons other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour” (Munger, 2003, n.p.).

has the greatest percentage of visibility minorities regionally (12.9%), but again this is still considerably less than the provincial average. Our project consisted of a similar breakdown, with 6 of the 25 participants self-identifying as a member of a racial minority group.

Niagara region's large geographic area, social and organizational structures present access challenges for residents across the region. The participants in the program are living in a region where understandings of disability are primarily informed by medical, charity, and faith-based approaches to disability that are reflected in the local service organizations. They have limited or no access to local disability positive spaces. In addition, because the participants are living in an area with limited to no access to public transportation, providing transportation support was a necessity for ensuring access.

Next to Lead – Project Overview

Next to Lead (NTL) was a three-year project (2016-2019) focused on developing young disabled leaders (age 18-29 years) living in the Niagara region³. The project was a partnership between the Niagara Centre for Independent Living (NCIL) (Executive Director, Maureen O'Neil) and the Department of Physical Therapy, University of Toronto (Karen Yoshida, PhD) and was funded by the Ontario Trillium Foundation (OTF). As outlined, the focus of the project was to develop leadership and community activism skills among a diverse group of “disabled youth” in the Niagara Region. The term “disabled youth” was used to satisfy the parameters of the OTF priorities for funding (youth aged 18- 29 years). As Steinberg (2009) argues, “youth” is a rather recent phenomena, constructed to depict a stage of development prior to adulthood. We

³ We would like to point readers to the final toolkit developed for this project. The toolkit comes in the shape of an interactive webpage on the NCIL website (forthcoming). There, visitors have access to many of our written materials, presentations, and videos we used throughout the project. There are also links to the materials and videos participants created as part of their work in the project.

reject such a characterization and consider youth development as “culturally and socially defined by the surroundings and experience of each young adult” (Steinberg 2009, p. 273). Thus, our framing is to reject the binary these categories produce and suggest that “young adults” may be a better descriptor for the individuals involved. While we may want to fully characterize our participants as adults, by doing so we do not want to suggest that youth cannot lead and are not already leaders.

Participants interested in Next to Lead had to self-identify as disabled persons, reside in the Niagara region and be interested in learning about leadership and social justice. Participants also needed to commit to being involved in the full duration of the project. We aimed to include a diverse and a cross-disability group of interested participants. Given that the Niagara region was nearly devoid of disability positive spaces (except for NCIL) recruitment strategies were extensive. For example, we produced a variety of promotional materials – e.g. posters, rack cards, social media pages, and a website. As appropriate, materials and requests for participation were directed to any and all spaces and services that disabled young adults might visit or access. For example, contact was made at community fairs, intra- and inter-agency meetings and individual meetings with service providers. Print materials were left at popular cafes, event venues, social service agencies, employment centres, and recreation/sports clubs; as well as spaces that were accessible and inclusive to disabled people. Interested participants came from three main sources – academic institutions in the region, intra-agency services, and NCIL. We had 45 inquiries, contacted 35 (nine were ineligible) and started the project with 26 participants. Study participants reflected diversity in age, geographic area, gender, race, and disability. We had 12 female-identified and three male-identified young adults that ranged from 20-29 years of age. Participants self-identified as living with ADHD, Autism, Epilepsy, psychiatric differences,

physical disabilities, and sensory disabilities. Participants also identified as Black, White, Latinx, Middle Eastern, South-Asian, and Asian. We were unable to recruit any d/Deaf or hard of hearing or Indigenous individuals.

Workshop's Structures and Contents

The project consisted of 10 workshops over the course of two years. The first workshop focused on introducing participants to the concept of disability as a social construct by outlining the long history of disability – up to the modern American and Canadian disability rights movements. We discussed the models of disability, the concept of ableism, and encouraged participants to reflect on their own lives and experiences of discrimination. The second workshop focused on disability arts and culture. Dr. Eliza Chandler presented the possibilities and capacities of disabled and mad artists. Both workshops were designed carefully and used many active learning strategies. With this grounding in Disability Studies, the third workshop focused on participants envisioning what community issue they wanted to tackle for the remainder of the project. Participants were asked to complete the following two statements as part of this workshop: “I dream of a community that...” and “Things that get in the way are...” This process resulted in three community group projects: 1) Disability Awareness – focused on increasing disability awareness in Niagara, 2) Accessibility in Niagara Region – to increase knowledge of disabled people’s experiences in Niagara, and 3) Ontario Disability Support Program (ODSP) – wanted to provide clear information and advice to other young people about the experience of applying to and living on ODSP.

Participants self-selected into one of the three projects. Throughout the second and third years of the project, through workshops four through 10, participants focused on planning,

developing, and implementing each project. During that time, they had access to each other, the staff at NCIL and the other members of the research team, as well as to both disabled and non-disabled mentors, and a budget of \$1,000 for each group project.

A Methodology of Access

In this section, we elaborate on our methodology of access and highlight how it contributed to the program's overall goal of creating new activists and leaders in the Niagara region. We also describe some of the significant challenges in organizing and sustaining a project of this size and length. Most importantly, two members of the Next to Lead project, who are also co-authors, describe their experiences of access in the project. They describe what they learned from the project as well as their experience of learning, and what impact the program has had on their self-perception, their capacity for organizing, and their aspirations for the future. We start this section with one of those reflections, from Alanna.

Alanna's Reflections

I remember getting an email inviting me to apply to a project titled Next to Lead. At the time I was a University student who received countless emails about opportunities in the Niagara Region. It was rare that I read these emails in their entirety, as most didn't interest me, but something that day made me keep reading.

I am not a spontaneous person, but I filled out the online application for Next to Lead as soon as I finished reading about the three-year project. I was tired of being in denial of my disability. I wanted to meet other people with disabilities and I wanted to make a difference in my community. What did I have to lose?

When completing the application for Next to Lead, I was asked what I believe makes someone a good leader, a word I would have used to describe myself before my disability consumed my life. I didn't think I had what it took to be a leader anymore.

I remember hesitantly checking off the box that stated, "I self-identify as having a disability," unsure if I had made the right decision in applying. In my mind, accepting that I had a disability meant accepting that my body was never going to "get better." It meant that my body was falling apart and there wasn't anything I could do to stop it.

I have Ehlers Danlos Syndrome: Hypermobility Type, a connective tissue disorder. Connective tissue is the body's glue, it is what the body uses to provide strength and stability, but I have faulty connective tissue resulting in problems with my joints, tendons, ligaments and nerves. I have struggled with EDS, chronic pain and fatigue since I was 14 years old. In the last 12 years I have had countless injuries, 12 surgeries, endless appointments for diagnostic imaging and injections and have spent more time with my surgeons and specialists than my friends.

I had been reluctant to join social justice projects or volunteer anywhere since my health drastically declined. I was unsure if my disability would be accepted, and if it was, could I even be accommodated? Who would want a volunteer who often needed time off or couldn't perform any physical tasks? Transportation and the costs associated with volunteering were also major concerns. If I am being honest, I also lacked the confidence to own my disability and to tell others what I needed in order to succeed.

I was overjoyed when I was accepted as a participant in the Next to Lead project and I knew as soon as I arrived at the first workshop that I had made the right decision.

I was able to participate in Next to Lead because transportation costs were covered, the workshops were hosted in a comfortable accessible space, frequent breaks were given, great food

was provided and most importantly the people involved accepted everyone. For the first time in my life I felt like my disability didn't limit me, it enabled me.

Next to Lead allowed me to become friends with people who could relate to the difficult thoughts and feelings that often accompany having a disability. The thoughts of "How long is too long to stay on the couch?" "What am I going to do if I am never able to work or look after myself?" "What if the pain continues to get worse?" The feelings of anxiety, fear, hopelessness, frustration, anger and sadness.

Each time a Next to Lead member shared a personal story at one of our meetings, it reinforced that I wasn't alone. Hearing everyone speak so openly and honestly gave me the confidence to share my personal story and the courage to accept my disability. Being a part of Next to Lead has made me feel less alone in the often-isolating world of disability.

The meetings and workshops allowed me to focus on improving my leadership skills while learning about how to advocate for improvements in our community for those living with disabilities. Next to Lead reignited my passion for advocacy work and gave me the confidence to stand up for not only my needs but for the needs of others as well.

Before Next to Lead I hid my disability. When someone asked why I couldn't lift something, I simply told them "I have a bad arm". If they asked why I was limping it was "I have a bad ankle." These simple answers seemed to satisfy most peoples' natural curiosity. On the rare occasion individuals continued to ask questions, I reverted to saying, "I just had surgery," which usually ended the conversation. The problem had been "fixed" in their mind and that was all they needed to hear.

Now if someone asks why I can't lift something or why I am limping I explain the injury, and if they are curious and continue asking questions, I tell them that I have Ehlers Danlos

Syndrome. It is my hope that by talking about my disability it brings awareness to EDS and that it gives others the confidence to talk about their disability too.

I am grateful for participating in Next to Lead, the courage it gave me to accept myself and the new friendships I have made. I hope to continue to use the leadership skills I have gained through the program to create positive change in the Niagara community.

Funding

Alanna's reflection highlights the positive impact the project had on her self-perception as well as her understanding of her disability. These changes were possible because, as she says, the project was thoughtful in its approach to inclusion. We have described this approach as a methodology of access, and one of the most significant tenets of this methodology is that it often requires funding. Next to Lead received \$287, 200 from the Ontario Trillium Foundation. Accessibility for participants was second only to staff salaries. We allocated funding for American Sign Language (ASL), live captioning, transportation, accessible meeting rooms, food (of all kinds and keeping in mind that vegan, vegetarian, gluten-free, dairy-free, kosher and halal prepared food is sometimes more expensive), and materials in large print and braille. We also included a line item that would see each participant receive a new iPad as well as any additional software or apps and or hardware (screen holders, etc.) that would ensure the tablet was accessible to each of them. Funding also ensured that we could provide participants with one-on-one communication with two dedicated staff members (one full-time and the other part-time) and this, we discovered was essential since many of the participants preferred to communicate via text or phone and not necessarily over email or through various social media platforms.

Funding was essential to creating an accessible project. Many well-funded projects fail to provide participants with these basic accommodations, always imagining non-disabled participants in their research or community projects or only thinking to provide individual accommodations, rather than considering access as a fundamental component of research design. We would encourage researchers, more broadly, to have access as a line item in every research project, regardless of what community or group they are recruiting from; disabled people are everywhere and excluding them from participating in research or community projects because those projects are inaccessible reinforces disabled people's invisibility/absence from everyday life.

We are also conscious that funding is still largely a process wrapped up in politics. We've reflected on Rachel Gorman's (2000) contention that program funding in Ontario is often, "granted based on the acquisition of skills that conform to perceived market requirements and social norms" (Government of Ontario, 1997, n.p.). Next to Lead, a project focused on youth acquiring 'leadership skills' for the purposes of entering into volunteer roles, could fall squarely within Gorman's criticism in that the project was sold as a way to teach disabled youth to more appropriately participate in activities that, in the end, profit corporations. However, teaching disabled people to 'lead' is also radical. It reframes what a leader looks like, how they might talk or think, and how they might lead. We also reframed leadership for participants throughout the project. Leadership was discussed and practiced as an interdependent project. We described how disabled leaders follow, as much as they lead. They listen, as much as they talk. They understand their leadership as connected in various ways with other people and materials in the world. Others may not define this as leadership, but as activism. We opted to conflate these concepts, as a way to ensure funding. The term activism is one that jars funders. We assume they envision a

project only interested in training participants in social mobilization. Our focus was much broader and started with introducing participants to their shared history as disabled people; to their shared culture through disability art, and their shared futures, yet undecided and still changeable. We were teaching them about leadership as disabled people, and that alone is activism in action.

Local and Focused

Our methodology of access also ensured that the project remained local, and that experts, mentors, and participants' experiences would stay in their communities. We therefore allocated funding to bringing resources, mentors, and experts to the participants in Niagara. This meant that the Toronto researchers (Karen Yoshida and Fady Shanouda) would travel regularly to the Niagara region, that experts or mentors in Toronto would also make their way to Niagara, and that we would also invite speakers and other experts (in public speaking, local activism, etc.) to join us in the workshops, always located in the participant's larger community.

During planning, and as a way of staying local and also ensuring that participants took up space (in their communities), we envisioned that workshops would be held in different locations, with each new site reflective of the topic of the workshop. Workshops with a focus on history would be conducted in local museums, on disability arts and culture in theatres or nearby art galleries, and on activism in local union offices. In the end, this proved challenging with many of these sites either physically inaccessible or unavailable during the times we needed. Even meeting at the local university proved difficult because of policies that prevented outside food on the premises.

We opted to hold workshops in community and civic centres, and also at a local non-for-profit aimed at providing accessible nature-focused educational programming to young people. With a large room, accessible bathrooms, wide doors and a variety of meeting spaces (and with the option to bring in all types of foods), Heartland Forest served as one of the primary places that participants met, learned, and discussed. To both occupy space in their community, and also experience access – both inside and outside (Heartland Forest has accessible trails and treehouses along its property) – participants could, again, imagine other spaces and places in their world differently.

Besides the importance of being in Niagara physically, a local/focused methodology of access also ensures that the topics under discussion are also local and focused. We could easily have generated discussion on issues of a global nature – of barriers and challenges that impact disabled people around the world. However, by keeping the issues focused on their lived experiences – such as issues with transportation, housing, around ODSP, awareness, and access in their communities, participants had stakes in what they were learning. The list of issues may seem familiar to disabled people and researchers of disability in other communities, and as part of our work, we instructed participants in the similarities and differences between communities. For example, discussions around transportation – physical access, cost, frequency, distance of travel, time involved in travelling – were compared and contrasted to issues experienced by disabled people in Toronto, not to conclude that the problems were the same, but to demonstrate to participants that their local actions, and potential changes, could also have wide-sweeping impact on issues in other communities and cities. We suggested to them that what happens in Niagara could encourage or spark change in other places.

Intimate, Relational, and Interdependent

Intimacy, relationality, and interdependency are three different concepts that could be their own points of access within this methodology. However, they also so clearly overlap. We were committed to creating a sense of safety and closeness, and to making a space that participants could be successful in. Ettlting (2001) calls such a space a relational space and describes it as “...where it is safe to do one’s transformative work” (n.p.). One of the primary ways we created such a space, besides dedicating funding to resources, was to construct organizational and structural arrangements within the project that would ensure participants felt comfortable and safe throughout the project. Examples include direct access to coordinators - personal cell phone numbers, work lines, and emails; constant and personal communication between participants and staff; and access to staff through social media. During the first few workshops intimacy and respect were established through exercises such as building a community agreement - a list that outlines how we would speak and interact with each other, and what we all needed to learn together. Items participants generated include simple things like, “be kind to one another” and “be supportive”. More challenging items on the list are “avoid assuming” and “be mindful of how much you say and encourage others to talk too.” Creating a community agreement was important not just for developing in participants a sense of control over their learning space, but it also proved useful when safety was a concern and tensions arose between participants. Referring to the community agreement was a way for us to discuss points of tension. We explore this idea further, in the section that follows.

During workshops we also engaged in activities that would create intimacy. We define intimacy as a feeling of comfort, where one can express themselves and where collective bonding might take place. Exercises like drawing, colouring, or other creative expressions were

regularly encouraged and part of the project's curriculum. Ettling (2001) argues that including creative ways of learning is just one more practice that can make participants comfortable - having a chance to express themselves non-verbally.

Intimate and relational space is important, but for disabled learners, we were also cognizant of the need to create space for, and acknowledge the value of, interdependency. We acknowledge that one of the ways that intimacy was created among the group was through interdependency - when participants shared a table, when one assisted the other finding a page, when they brought each other water or food, when requests for clarification or repetition were greeted with enthusiasm and compassion. Participants helped each other, but there was also a team of people present in each workshop to ensure their success through the project. The ratio between staff and participants was always reasonably high - nearly 1:3. There were often no less than seven staff and support persons at each workshop (attended by about 25 participants). Besides the two principal investigators (Maureen O'Neil and Karen Yoshida), the consultant (Fady Shanouda) and at least two members of staff, there were also volunteers and personal support workers, some hired by the project, others invited by participants.

Beyond support from personal support workers and staff, our project also anticipated technological needs, and welcomed (quite enthusiastically) the support of service animals. This web of support and assistance that included human, non-human, and more-than-human elements ensured that participants were well taken care of and could then also take care of each other and learn together.

Curating Access

Our methodology of access also included those points of access so many of us have become familiar with. These include acknowledgement of Indigenous land, introductions that include correct pronoun use, access check-ins, providing written materials in accessible formats, captioning videos (and having them audio described - if possible), and audio describing still images and other figures (charts, graphs, etc.), sending materials ahead of time, or having them available in print and digitally. Although these may be familiar to many scholars and educators, this will be new information to an equal number of individuals (both inside and outside of academia). More importantly, many community projects will not have dedicated resources and time to seeing these practices included in the projects. We hope that by having access to our website (forthcoming) community organizations will be able to make new and existing projects more accessible easily.

Other less familiar access practices include the community agreement (which we've already discussed) as well as a handy glossary of terms, developed by our first project coordinator Jenna Cooper. These glossaries, which participants could find in their package of materials at each workshop included definitions, examples, and phonetic pronunciation of many of the words we would be using in that day's workshop. For example, for the term sterilization, participants would see the following:

Sterilization

Pronounced: stare-ill-eyes-ay-shun

Sterilization refers to any medical procedure that purposefully makes it so that a person cannot have children.

Example: In the past, society worried that disability could be passed down through generations, so they attempted to sterilize disabled people.

Following Gorman (2000) and others, definitions and examples were in plain language, and clear and focused on conveying the most important ideas.

A central part of curating access for this project was to take things slow. Participants learning was not rushed. Taking time is a luxury. It is contrary to how the university operates today, much less the rest of the world. However, we opted to go slow in order to give participants an opportunity to learn, and reflect, and push back in a timeframe that was not just realistic, but indulgent and forgiving. We also expected that much of learning would happen in-between workshops, and not just during them. As such, going slow also meant that participants were steeped in counter-dominant discourses about disability for long periods of time - a rarity for any group of individuals.

Throughout the project, workshops were spaced a few months apart. To ensure participants were learning outside the workshops, we sent materials, videos, and resources before each session as well as connected with participants after each session, either over the phone or email or through social media to clarify ideas or plan for next steps. Going slow gave participants time to process, to question, challenge and/or accept the ideas presented. Staying in touch in-between workshops meant participants could communicate their agreement, disagreement, or confusion about an issue and that team members could respond, consider their point of view, and make changes to the following session. Therefore, going slow allowed us to make changes. For example, we added four workshops after participants requested more meetings with each other (the budget allowed for this because we did not use up funding allocated for ASL). Our pacing also allowed us to get to know the young people we were working with. To learn about other parts of their lives, their interests and talents. It allowed us to build connections that we hope will continue now that the project has ended. We encourage

going slow as a way of ensuring access, however, we did hear from participants that our pace may have been too slow.

Finally, we have already highlighted in the literature section of this paper so many of the other points of access that have been practiced and recommended by other scholars and activists working within academia and in the community. One might imagine that in combining the list in this section with the one above that everything would be covered. This is not the case. There are still things missing from our methodology. We have not discussed live captioning, the use of microphones, identifying oneself when speaking, a coloured dot system to reflect mood and willingness to interact with others, the inclusion of communication facilitators and visual note takers, and the list could go on. There are, of course other ideas. Ideas *out there* that we have not experienced or practiced, ones we do not yet know or can even imagine. These possible points of access intrigue us because they remind us that we will fail to create a totally accessible space. Failure haunts this kind of work, and that is something we urge others to accept, and maybe even revel in.

Welcoming disruption: Desiring embodied differences

Maybe the most important tenet of our methodology of access comes from Mia Mingus. In describing the importance of access and its limitations, Mingus (2010) writes

Accessibility is concrete resistance to the isolation of disabled people ... We must, however, move beyond access by itself. We cannot allow the liberation of disabled people to be boiled down to logistics. We must understand and practice an accessibility that moves us closer to justice, not just inclusion or diversity. (n.p.)

She challenges us to move beyond access; of listing the barriers - physical, environmental, informational, communicational, attitudinal, organizational or systemic - and checking off on a list those tried and true interventions. Access must go beyond those lists - “the logistics” - and must include justice. Mingus says this is accomplished if we “move away from the ‘myth of independence’ and instead embrace the reality of interdependence. However, we argue there is another element to thinking and acting beyond access. This is “...to open up desire for the way that disability disrupts” (Chandler, 2014, p. 30). That is to allow for what cannot be planned or imagined. To be spontaneous. To make adjustments. To desire what cannot possibly be planned. To crowdsource solutions. To allow the slippages and leakages that comes with disability and madness.

These are moments when we go beyond the access we have imagined, and it is often for things that we could not have planned. Someone feeling unwell and helping them find and take their medication; a late arrival that results in tension between a driver and a passenger; a triggering activity remedied only by working one-on-one with a caring and attentive staff member. Some will qualify this as practicing empathy (and it is) and that it should therefore be common sense. However, we would respond to such criticism and argue that this is more than just responding to interruptions or crises when they arise. This is about expecting disruptions and embracing them as a means of ensuring access.

We might summarize this section on thinking beyond access as welcoming failure. To think and act beyond access is to anticipate failing at creating an accessible space yet working towards that goal. In speaking to this idea of access failures (in their own compelling approach to access between academics and artists) Ignagni, et al., (2019) argue that we must be careful about our desire to “bounce back” to “confirm, rather than subvert, the demand to ‘not fail’” (p. 308).

In calling attention to this issue, Ignagni, et al, (2019) reminds us that to try to meet every need, to respond as if failure is not a choice, is in itself an exercise in overcoming. We welcome failure in our methodology of access because it means we might generate something else - something new. We close this section with Y's reflection on the project and her experience of our methodology of access.

Mah-E-Leqa's Reflections

Disability does not discriminate. It does not look at your financial situation, your ethnicity, your gender, your religious beliefs, your health, or your environment. Disability is not an independent factor in an individuals' life, rather it is an overall part of one's existence. Three years in the Next to Lead program taught me all of that. It may seem like a simple learning outcome but putting disability into perspective is more involved than the above statement.

I was diagnosed with Charcot-Marie-Tooth Disease at two and a half years of age. For 21 years, all my disability meant to me was a medical problem - weakness, adapting to the world around me, and being different from everyone else. Going through the Next to Lead program, I learned to look at my disability socially. I learned that my disability is not just a medical diagnosis, but it is truly a part of my existence. Not just accepting my disability, but to accept myself as a whole person with dreams, aspirations, and challenges is what I learned from Next to Lead.

Before I could go out into the world and teach people to understand and accept disability as a leader, I had to do that myself. I needed to be comfortable with being disabled first. It's easy to expect people to change their mind about disability, but that expectation is unrealistic when we know that disabled people have a hard time doing this first. One of the best things I

discovered about Next to Lead was that I was in a group of like-minded individuals who were all learning and becoming leaders. We all equally had great experiences, thoughts, ideas, and skills to share.

The Next to Lead program did a great job of making sure participant needs were being met. For example, before any workshop, participants were given a chance to state any access needs they may have during an access check-in. To make sure that everyone had an equal chance to participate in all activities, transportation was provided. Even social activities were planned with accessibility in mind. I remember going to the “Reclaiming Our Bodies and Minds (ROBAM)” conference in Toronto and the walk from the bus station to the university was too far for me and so a cab was called for me because I got tired of walking. The project coordinators, facilitators, and other staff involved truly wanted us to succeed and were always concerned about whether we were okay and fine. If things were moving too fast, the project coordinators tried to slow the pace. The participants were very understanding of each other’s needs and created an environment where we supported each other. It is noteworthy that since the cohort of participants was relatively small, there were little conflicts that were generally easy to resolve.

I was eager to learn throughout the program. The amount that I have learned in all the workshops is unbelievable! I not only learned from the content given to me, but I also learned from the people around me. Furthermore, I learned that disability is not just about efforts that are taking place today, but also what has been going on in the past. For example, in the first workshop, we reviewed disability history and the social implications of disability in society and how leaders have emerged as a result. Those efforts have and are shaping our ideas around disability today.

In the Next to Lead program, I not only learned leadership skills, but I applied them. I worked with a group of individuals on accessibility. We collaboratively shared our experiences and created a PowerPoint presentation that we presented in front of two large audiences. As a leader, I was given the opportunity to let others know what accessibility is like in Niagara for disabled people.

Through Next to Lead I realized that there are many tools and opportunities available to me to work with my peers to lead social change to try to mold a different mindset that sees beyond limitations and to continue to celebrate individual abilities whatever they may be!

Resolving Tensions within a Methodology of Access

A methodology of access, in addition to creating a sense of community, it also creating points of tension at certain times during the project. These points of tension occurred in some of the everyday modes of access we used, in a lack of patience for others and, in a rare situation when there was a lack of respect for boundaries in communicating outside of the project.

Some daily tensions around access occurred in the pacing (speed) of sessions. In evaluations from each workshop session, many people believed that the pace was fine, but a few participants requested summaries of the last workshop prior to the beginning of the next workshop. We handled this by working one-on-one with these participants to allow for them to catch up. However, participants who had missed a few sessions, were not always able to integrate themselves back into the group and one participant left the project for this reason. Thankfully, this individual continued to work with NCIL in another capacity. We did have a person who felt unsettled during a workshop. We responded quickly when this did occur, but on reflection could have done things differently to mitigate the situation. Although we did access

check-ins at the beginning of every session, these are open and collective calls for change/access that only address people's level of interaction collectively. We now might also include individual check-ins with participants to invite them to let us know privately how they are feeling. For future work in this area we will be more proactive and check with the group and invite individuals to let us know how they are doing and what their needs will be, if any, that day. Again, from failure, another point of access.

There were some other points of tension – impatience and disagreements that arose during workshops sessions and group projects. This resulted in a few people leaving the project altogether and one person switching groups. In the final evaluations, participants responded that they felt that the project moved along too slow or too fast. In planning this three-year project, we did err on the side of having more time between workshops so that participants had time to learn the material and to connect with each other. We knew that participants were also busy with other aspects of their lives, going to school, working or trying to find work, so some of the issues related to the pace of the project may be related to this. Finally, we had one participant who did not respect the boundaries of another member over the internet. The offending participant and the other member had a discussion with the project coordinator, and this resulted in a refinement of the community agreement to extend outside of the project. We also had each participant sign an agreement indicating that they would respect each other's boundaries outside the project. While the offending participant rejoined the group at first, this individual again crossed boundaries on the internet and was therefore asked to leave the project. Given that the participants in general, did not know each other prior to the project and were busy with other things in their lives, it was not surprising that we had a few incidents of tension throughout the three-year project.

Conclusion

Moving forward, participants have considered taking action to respond to issues with transportation in the Niagara region, to developing and delivering similar programming to Next to Lead but for school-age disabled children in Niagara, and to lobbying for change to ODSP. These potential actions surprise and thrill us. They suggest that there has been a shift in thinking and in participants' self-perception of what they are capable of as individuals and as a collective.

Our aim in taking on this project in the Niagara region was to remove Disability Studies from where it has lived and thrived for so long now - Toronto and in academia - and to bring it back to the community and to young people who may not have access to this scholarship. We knew that in trying to launch such a venture would mean that it would have to be accessible. This meant time spent imagining who would be in the project, and how we might accommodate their diverse needs alongside the needs of a diverse group. Developing our approach, which we've only in hindsight named a methodology of access, was essential. A crucial process that was collaboratively developed, refined and executed by every member of staff, as well as, by so many of the participants. We are writing this paper not only so that others interested in reproducing this methodology have a guide, but also to encourage adult, transformative, and community-based scholars to write about their approaches to access into their work and to make it central to the research on pedagogy in community-based settings.

Alanna and Mah-E-Leqa demonstrate in their reflections the power and possibilities of education when it is accessible. Their contributions to our analysis in this article, as well as their work throughout the project - as with all the participants - is unquantifiable, but immensely appreciated. We understand that our proposed methodology of access is unfinished, and we will continue to work to improve it. However, what is more exciting to image is Alanna and Mah-E-

Leqa taking on this methodology and coming up with something better. Activists and leaders in their own right, they will have new ideas to add or refine; and this possibility is all we could have asked for in the end.

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