Disability, Sexual Health, and Participatory Video:
Advocating for Sexual Rights

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Abstract

This action research study addresses sexual health as a critical human rights issue in the disability community. Twelve participants engaged in the co-creation and editing of a series of videos about the dimensions of sexual rights as experienced and understood by persons with developmental disabilities. The participants also uploaded the videos onto digital platforms and took on the role of community educators while incorporating their videos into their larger advocacy campaign.

This article begins with a brief review of the literature on sexual health and disability, noting there is a paucity of research that considers storied narratives when exploring the topic of sexual rights and disablement. Drawing on critical disability theory and Freirean pedagogy, the second section explores how a group of adults with developmental disabilities used participatory video as an advocacy tool in disrupting colonial voices through reclaiming histories and leading discussions about their sexual rights. Further implications and limitations to this study are also addressed.

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) specifies that disabled people have the right to marry and parenthood (Article 23), the right to education (Article 24), and the right to have access to sexual and reproductive health care (Article 25) (UNHR, 2006). However, the violation of human rights is nowhere more prevalent for persons with developmental disabilities[1] than in the context of sexual health (Richards, Miodrag, Watson, Feldman, Aunos, Cox-Lindenbaum, & Griffiths, 2009). The World Health Organization defines *sexual health* as follows:

> Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well

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[1] The *Convention on the Rights of Persons with Disabilities* (CRPD) defines disabilities to "include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations Human Rights [UNHR], 2006, Article 1, p. 4). According to The Developmental Disabilities Association (2012), "developmental disabilities are generally used to describe life-long impairments that are attributable to mental and/or physical disabilities" (para. 1). Depending on geographical location, the terms "learning disability", "cognitive disability", and "intellectual disability" are also synonyms for developmental disabilities (Developmental Disabilities Association, 2012).

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> as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled. (WHO, 2006, p. 4)

Persons with developmental disabilities face extensive systemic, attitudinal and practical barriers in relation to their sexual rights, including minimal or non-existent access to sex education, intimacy, procreation, "and even loving another person of choice, if it at all resembles a sexual relationship" (Richards et al., 2009, p. 184). For instance, the 2011 *World Report on Disability* acknowledges that disabled people have significant unmet needs in this area, it also stresses that there is a paucity of research in the area of sexual health. Several disability scholars and activists have also emphasized limited accessible educational opportunities for persons with developmental disabilities (Gardiner & Braddon, 2009; Hingsburger, 1995, 1998; Swango-Wilson, 2011). There is also limited funding for services and the development of supportive policies for developmentally disabled people in the area of fostering positive sexual lives and healthy relationships (Evans, McGuire, Healy, & Carley, 2009; Hingsburger & Tough, 2002).

Discriminatory policies that fail to recognize persons with disabilities as sexual beings coupled with a denial of human agency further contribute to supporting and sustaining barriers to sexual rights for persons with developmental disabilities. Often, parents, caregivers, guardians, workers in care facilities and service providers have an overpowering influence in the lives of people with developmental disabilities. These individuals habitually play critical roles in the areas of emotional support, accessing and receiving information, and human connection. However, as Di Giulo notes, "there continues to be a high level of anxiety, mythology and uncertainty concerning the sexuality of people with developmental disabilities" (2003, p. 58). The underlying ideologies that support these barriers often come from infantilizing persons with developmental disabilities.

Dismantling barriers for individuals with developmental disabilities not only involves challenging ableist attitudes, but also calls for recognizing how ableism intersects with other areas (Sherry, 2004). For instance, compared to temporarily able-bodied people (TAB), people with disabilities have poorer health, lower education, and higher rates of unemployment (WHO, 2011). In Western societies, meeting people through university, employment, or leisure activities are rarely accessible options for persons with disabilities (Taleporos & Bowden, 2006). These barriers are further explained by Shakespeare:

> The barriers to the sexual expression of disabled people are primarily to do with the society in which we live, not the bodies with which we are endowed… Most people meet potential partners at college, at work, or in social spaces. Unfortunately, disabled people often don't get to go to college, or to work, or achieve access to public spaces, because of the physical and social barriers. (2000, p. 141)

Barriers are compounded when persons with disabilities are further discriminated against based on age, gender, ethnicity, race, and sexual orientation (WHO, 2011). Sherry (2004) also drew a comparison between the lesbian, gay, bisexual, transgendered, and queer community (LGBTQ) and people with disabilities' denial of sexual rights as a result of stereotypes. Sherry identified similarities such as familial isolation, high rates of violence, and discrimination.

Implications

Research findings reflect that developmentally disabled people are severely and repeatedly sexually abused (Fegan, Rauch, & McCarthy, 1993; Hingsburger, 1995, 1998; 2006a; Richards et al., 2009; Sobsey, 1994), and are at a significantly higher risk of sexual abuse than temporarily able-bodied persons (see Evans et al., 2009; Kelly, Crowley, & Hamilton, 2009;

Murphy & Young, 2005; Servais, 2006; Swango-Wilson, 2011; WHO, 2011). In Canada, 80 percent of women with disabilities and 54 percent of men with disabilities are sexually abused, and if a person is developmentally disabled, "the likelihood is that rape or molestation will be your first experience with sexuality" (Hingsburger, 2006a, p. 1). Hingsburger also indicated that 90 percent of abusers are in caregiver roles, and only 3 percent of offenders serve time (2006a). Further, in the 2011 *World Report on Disability,* which examined international developmental disabilities issues, it was reported that persons with developmental disabilities are vulnerable for sexual abuse and exploitation in both institutions and in community settings (WHO, 2011).

Over the last decade, the United Nations has recognized that the sexual rights of persons with disabilities are a human rights concern. The World Health Organization and the World Bank (2011) suggest one of the main solutions is to educate health care practitioners in sexual rights of people with disabilities. Kangaude (2009) also stresses that in the international arena, health care organizations need to lead in education regarding sexuality. Similarly, in Canada, Hingsburger (1995) advocates for education for caregivers and service providers, while also calling for early education for people with developmental disabilities.

Although scholars continue to explore the educational component in addressing sexuality and disability (see Clark & O'Toole, 2007; Richards et al., 2009; Servais, 2006), there are limited research studies that explore the perspectives of people with developmental disabilities in the area of sexual rights (see Esmail et al., 2010; Galea, Butler, Iacono, & Leighton, 2004; Kelly et al., 2009). Given the pervasiveness of sexual rights issues, there is a need to hear the perspectives of those people with disabilities experiencing injustice.

Self-Advocacy & Arts-Based Media: Participatory Video

Self-advocacy involves people with developmental disabilities advocating on their own behalf and favours approaches where people with developmental disabilities are at the forefront of the advocacy process (Block & Nelis, 2006). Self-advocacy has been critical in mobilizing advocacy efforts amongst persons with developmental disabilities, especially through the international development of the People First self-advocacy organization (Weafer, 2003). People First is run by and for persons with developmental disabilities to address civil and human rights issues (Block & Nelis, 2006). As of 2004, there were chapters in 43 countries with an estimated 17,000 members (Block & Nelis, 2006). Self-advocacy stresses self-representation in social action initiatives, where participatory and emancipatory methods are employed to explore the topic of sexual health and advocacy.

However, in the research surrounding sexual rights, the perceptions and opinions of persons with developmental disabilities often remain disturbingly absent. Although Hingsburger and Tough (2002) emphasize the critical importance of strong sexual self-advocacy by people with disabilities, there is a dearth of scholarship that explores self-advocacy in the area of sexual rights.

As disability scholar Shakespeare states, "disability identity is about stories, having the space to tell them, and an audience that will listen" (as cited in Sherry, 2006, p. 909). Barton further notes that:

> Particular slogans such as "Piss on Pity," "It's choices and rights not charity we want," reflect both recognition of the offensiveness of disabling barriers on the one hand, and the desire to identify and challenge them on the other. Underpinning this approach is a public affirmation of a positive view of difference. (2001, p. 7)

Sherry also suggested that the stories people with disabilities share about their lived experiences are critical in individual and collective efforts; positive narratives of disability help people foster pride, overcome internalized oppression, and develop conditions for collective organizing (2006).

Progressive social change in the area of disability rights has involved various arts-based tools that emphasize self-representation. By engaging in creative forms of expression and focusing on lived experiences, the arts have played an instrumental role in challenging stereotypes and in mobilizing support around political issues (Sandahl, 2006). First-person narratives have also been found to create a powerful and resonating representation:

> A sense of urgency is palpable in these pieces, a sense that the actual stories of disabled people have been ignored, silenced, or diminished and therefore must be told. Autobiography offers first-person testimony of life with a disability, a corrective to traditional stereotyped representations. This work helps to clarify pressing political issues and personal concerns for its audiences. (Sandahl, 2006, p. 406)

Collaborative, arts-based forms of representation are also of critical importance to self-advocacy. One such approach is participatory video. Participatory video is an arts-based method that involves community members collaboratively creating videos about topics and issues that are important to them. The origins of community-generated film for the purposes of social action can be traced to Fogo Island in Newfoundland, Canada. In the 1960s, a community partnership was formed with the National Film Board that involved Islanders developing a series of short films as an advocacy tool to challenge a resettlement policy (Crocker, 2003). The *Fogo Process* drew on principles of collaboration, community organization, and de-centering the notion of "expert." The approach also exemplifies how participatory visual media can be used toward self-advocacy, to influence policy makers, and contribute to individual and group empowerment.

Although there are various models of participatory video (Crocker, 2003; Guidi, 2003; Shaw & Robertson, 1997), there are certain elements most have in common: it is a group-based activity; community members create videos; and these community members are also involved in the video production process (Shaw & Robertson, 1997). Workshops are geared toward assisting individuals with minimal technological fluency: where participants, regardless of age, ability, literacy skills, or technological fluency, are guided through a process of collaboratively developing videos. Through this process, participants familiarize themselves with the technology while also creating project plans, storyboards, and video sequencing. Participatory video also calls for facilitators having skills and knowledge with video technology (e.g., sound, editing, lighting, techniques, cameras, etc.) (Shaw & Robertson, 1997).

There is also a growing momentum of using participatory video in disability studies (Ignagni, 2009; Ignagni & Church, 2008; Okahashi, 1998, 2000). These methods provide innovative forms of expression to amplify voice and honour narrative. For instance, Okahashi (1998, 2000) described a participatory action research study where people with developmental disabilities made videos about human rights laws in order to enhance the ability of individuals to access and understand their rights. Okahashi claimed that part of the potential for using participatory video with persons with developmental disabilities is that it offers an alternative for people who have difficulties with reading and writing (2000). The author stated that self-advocates can use participatory video as a tool for social change by documenting histories, and sharing stories, which can build connections within the community when publically screened (Okahashi, 2000).

Research Background

This article reports on one area of a larger action research study that involved members from a North American advocacy group who collaboratively created and shared 14 short participatory videos that explored the dimensions of sexuality, sexual health, and sexual rights in the disability community as experienced and understood by persons with developmental disabilities (Sitter, 2012a). Susequently, participants became community educators and distributed the videos through a number of communication channels and settings.

Profile of Participants

A total of nine advocates with developmental disabilities and three allies, all of whom were part of the advocacy group participated in the study. Participants were not asked to elaborate on any personal impairments[2] however all advocates indicated that they self-identified as persons with developmental disabilities.

There were seven males and two females who were self-advocates, three allies and myself, who were all female. All participants were adults, between the ages of 28 to 58. All participants were Canadian citizens[3]; 12 of the participants were White and of European descent, and one was Filipino-Canadian. There were various stages of sexual experiences and different sexual orientations amongst participants.

Positionality of the Researcher

As a filmmaker and community facilitator, I have worked in community-based projects using multiple forms of participatory visual media. My experiences over the last 10 years have led me to reflect on the creative process of developing visual media that both honour and amplify voices, and the role images can play in shaping critical thought, raising awareness, and social action. The ideological lens through which I see and experience the world has been profoundly shaped by my identity. My Whiteness, education, and social status as a temporarily able-bodied (TAB) woman have provided me with opportunities in the areas of work, school, and various levels of personal choices related to relationships and starting a family, these are choices that I recognize are not readily supported for many people with developmental disabilities. In this research, I attempted to hold onto an awareness of how a history of inequality has impacted, and continues to impact, those with disabilities, and their right to be treated and recognized as equal members in our society. My “outsider” status as a TAB is tempered by my experience collaborating with a disability organization on previous film projects where I facilitated community workshops and was involved as an editor with the annual disability film festival.

Theoretical Orientation

Critical disability theory and Freirean pedagogy are the theoretical orientations that informed this action research study. Critical disability theory (CDT) draws on a social model of disability and represents an integrated approach to critiquing disabling structures to achieve social, political and economic change (Meekosha & Shuttleworth, 2009). CDT also draws on critical race theory (Hosking, 2008). The influences from critical race theory include recognition that racism is ordinary and pervasive. From a critical disability orientation, this recognition is reflected in implicit ableist attitudes and systems. CDT also draws on the role of storytelling, which is also a core tenet of critical race theory (Campbell, 2008). For instance, Delgado and Stefanic (2012) explicate how storytelling can contribute to naming and addressing internalized oppression:

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[2] Part of the video process involved an exploration by participants into the dynamics of the disabling barriers they face in the area of sexual rights, which reflects a Critical Disability Orientation and social model framework.

[3] People did not provide details of their cultural background and it was interesting that, in developing the videos, people did not discuss their cultural background in detail.

> Storytelling also serves a powerful additional function for minority communities. Many victims of racial discrimination suffer in silence or blame themselves for their predicament. Stories can give them voice and reveal that others have similar experiences. Stories can name a type of discrimination; once named, it can be combated. (p. 49)

A critical disability orientation is also concerned with the intersectionality of disability identity where disability is fundamentally diverse and intersects with class, gender, race, sexual orientation, ethnicity, and other social categories (Hosking, 2008; Meekosha & Shuttleworth, 2009; Pothier & Devlin, 2006). Critical disability scholars are also concerned with how disabling attitudes are revealed and supported through language and media. This orientation also stresses the importance of self-representation in transformative politics, which aligns with self-advocacy. The engagement of arts as voice also draws on critical disability as it builds on privileging stories of disabled people and honouring lived experiences. In exploring the use of participatory video in advocating for sexual rights, CDT provides a relevant and useful theoretical framework that supports a critical orientation.

Freirean pedagogy provides the foundation for participatory-based video to engage in social transformation and conscious-raising methods that value community-led learning. While adhering to an emancipatory stance, Freirean theory lends itself to informing a critical disability orientation as it calls for inclusive research that recognizes and privileges knowledge derived from people’s lived experiences (Connor, Gabel, Gallagher, & Morton, 2008).

Data Collection and Analysis

Data collection occurred over 12 months. For the first 4 months, 2-hour meetings occurred approximately twice a month in the community building that acted as the central location. There were monthly meetings during the distribution phase, which lasted 8 months. Both the filming and the community presentations occurred outside of these meetings.

During pre-production, we engaged in arts-based activities to generate the goals and foci of the videos. The generative themes that grew out of these arts-based activities guided the topic of the videos. These themes were then put on a storyboard, where we worked together to decide 1) who we would like to interview in the community, 2) develop interview questions, 3) create an overall filming schedule. Prior to filming, all participants participated in a video workshop that was facilitated by myself and another filmmaker. The video workshop consisted of exploring different roles such as camera operator, interviewee, interviewer, and director as well as watching and commenting on the footage from the workshop. Filming then occurred at various locations, where participants decided how they would like to participate both in front of and behind the camera.

The post-production phase involved viewing the raw footage together and talking about the ways in which the videos relate to lived experiences. This process of engagement further demonstrates Freirean pedagogy where community members explore the interconnection between oppressive social structures and their own experiences (Freire 1970/2008, p. 84). This process also entailed collaboratively deciding video sequences and reshots. In the end, 14 short participatory videos (3-5 minutes in length) were created that were based on the themes identified in the pre-production stage. These interconnected themes included: (1) human rights (2) the role of advocacy; (3) histories; (4) barriers; (5) required supports; (6) relationships; (7) life stories and experiences. The participants subsequently shared these videos within the wider community in both formal and informal settings such as presentations, workshops, and virtual settings. In the following sections, I explore how participants used participatory video to disrupt colonial voice through reclaiming histories and challenging hegemonic messaging through self-representation.

Disrupting Colonial Voices: Our History[4]

During one meeting, a participant brought in a series of photographs to share with the rest of the group. While talking about the images and which ones we should incorporate into the videos, several participants stressed the need to include a specific photograph that was taken at a disability pride event. In this image, two of the participants are dancing in front of a Famous Five statue. The Famous Five are a group of Canadian women who advocated for the rights of women at the turn of the century, and were instrumental in the 1929 ruling where women were legally considered persons (Hughes, 2001/2002). Although I was familiar with this part of Canadian history, I was unclear why members of the group adamantly wanted this image in one of the videos. I asked them why it was so important to include this picture. One participant explained what I did not know at the time: that several members of the Famous Five were also strong supporters of the eugenics movement and were key in the passing of the Sexual Sterilization Act in Alberta in the 1920s (Koshan, 2008).

The theory of eugenics, a term coined by Francis Galton to describe selective breeding, was predominately based on class, whereby the lower class people were labeled as “degenerate” with a definition that included a list of characteristics deemed hereditary, including intellectual and physical impairments, poverty, alcoholism, and “deviant” sexual behaviour (Malcomson, 2008). During the early part of the 20th Century, with the growing urban centres in North America, there was also an increase in social issues with crime, overcrowding, and illness (Malcomson, 2008). Social reformers presented a number of solutions to these living conditions, one of which was the practice of eugenics. The eugenics movement received strong support across Canada from academic scholars (Normandin, 1998) along with more political figures endorsing eugenics and sterilization, such as the Famous Five members Nellie McClung, Louise McKinney, and Emily Murphy (Grekul, 2008). Based on the eugenics philosophy, the province of Alberta[5] passed a Sexual Sterilization Act[6] in 1928. (Grekul, Krahm, & Odynak, 2004). Under this Sexual Sterilization Act, from 1928-1972, 2832 people were sterilized, the majority of whom included women with disabilities who were involuntary sterilized (Malcomson, 2008).

In our discussions about the image where participants are dancing in front of the Famous Five, participants also stated that historical topics in the Canadian landscape often exclude the voices of persons with disabilities, and historically, sexual rights and disability are rarely discussed. “The right to love is far from being accepted in Canadian society” (Participant). Several people felt the history of eugenics and the Sexual Sterilization Act in Alberta are often unknown amongst the majority of Canadians, as well as the experiences of those who lived through this historical period and advocated for their rights. For several participants, the photograph of the Famous Five Statue symbolizes the historical barriers for persons with developmental disabilities and their sexual rights, whereas individuals who are dancing in front

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[4] This section “Disrupting Colonial Voices: Our History” has been previously published in detail. See Sitter 2012b.

[5] The B.C. government also passed a Sexual Sterilization Act in 1933. However, the number of people who were sterilized under the act is unknown as the documents were destroyed (see Malcomson, 2008).

[6] Eugenics also garnered significant momentum amongst McGill academics and Quebec politicians; however, the Catholic Church was instrumental in resisting any legislation of sterilization. During this time, the Roman Catholic Church had a strong hold in both political and educational realms throughout Quebec and viewed sterilization as a form of birth control, which went against the church doctrine (Normandin, 1998).

of the statue and the inclusion of the image in the video demonstrates a reclaiming of history from the perspective of disabled people.

Participants also emphasized that creating these participatory videos further required reclaiming their histories from their own storied narratives. For instance, during the editing process, participants viewed several videos of people telling personal stories that occurred when sterilization was legal in Alberta. In one interview on film, a participant describes her dating experience as a young adult. After viewing this film, another participant reminded us that the historical context of this story is a critical piece: "[This] story happened in the 1960s, when institutionalization and sterilization were legal in Canada. Her story is historically situated during a time where discriminatory practices were protected under the law."

Another individual who also lived through this historical period pointed out the strength and resiliency inherent in this person's story:

> What I found was that she stuck up for her rights about having boyfriends and going out on dates. During that time, disabled people weren't allowed to mingle or fall in love, I recall. She did a good job sticking up for herself. She got her wish. She was too stubborn to listen to her parents. She listened to herself instead of her parents. She stuck up for herself against her dad. She had the right to date. She stuck up for herself, and that was good. Right on [name of participant]…right on. (Participant)

A number of participants stated this historical timeframe is a critical piece to this personal video, as it further acknowledges the interviewee's strength in advocating for her rights during a time when rights for persons with disabilities were suppressed under the law. The participant featured in the video agreed, and the final film included a voice-over that situated the story in a historical frame: "This was the 1960s. During this time it was rare for people with disabilities to be living at home. Institutionalization and sterilization were also legal in Canada."

Challenging Hegemonic Messaging through Self-Representation

"We are the ones sharing our stories. We are the ones in the film. It's us." (Participant)

Several participants indicated there was power in hearing each other's stories and found that watching personal videos also solidified a shared understanding of some of the issues. For instance, in one video, a participant described a story of how he met a woman and brought her back to his place, only to be interrupted by his roommate in a very awkward moment. He hopes that his story will help audiences understand that "people with disabilities have sex and funny stories just like everyone else, and they happen in funny, unique and challenging ways." After viewing the video, another participant further explained the power of storytelling: "what you had to say struck a chord, especially when you talk about the sharing of stories and the fact that we all have stories to share and that's often not realized".

In community presentations, the films also acted as a catalyst to discuss sexuality, often evolving into detailed conversations about sexual rights. During the screening of this video, an audience member said that in her experience working as a support worker, choices and decisions in the area of love and sexuality are also part of a larger issue of lack of social citizenship:

> People with developmental disabilities are often infantilized, sheltered, and don't have opportunities to do these things, and to make mistakes. They aren't taught at a young age to make decisions, because decisions are always made for them; the decisions are taken away. They don't have any rights. Even on surface decisions. And it's so entrenched that they don't have voice. (Audience Member)

Another participant stated that showing the videos to family members presents an opportunity for parents to understand how denying their sexual rights have an impact on their overall wellbeing. For instance, one participant shared the mixed messages he receives from his parents compared to what his peers say to him in this advocacy group:

> Participant 1: It's wrong for me to love. My dad thinks it's wrong, and my mom thinks it wrong. But I was born a sexual human being. Why is it wrong for me to love someone?
>
> Participant 2: You're gonna get a copy of the film, and you can show your parents. Maybe that will help.
>
> Participant 1: Yea, maybe it will help. Videos from disabled people saying that it's right to love, rather than it's wrong to love.

Before making the films, another individual said she was unable to talk with her parents about love and sexuality, but the films gave her courage to open up the channels of communication; after sharing the videos a few times with her mother, this participant reiterated that, "I was really proud. It's not easy to talk about your stories. Especially if someone's hurt you, or if you feel like you're the underdog. It's kind of scary... [but] the more you talk, the more things can change."

Positionality, Power, and Sites of Resistance

> *It's about changing values so that there isn't just pride within our group, but there's an awareness beyond our group. It's about social action. (Participant)*

Members of the group also discussed how negative perceptions of disability create systemic barriers because individuals "are not considered fully human" (Participant) by many people in society. Using a metaphor, one individual emphasized the problematic juxtaposition of disability and ableism in defining what it means to be human, and reiterated the need to attend to stories in the film that emphasize humanity:

> We just need to be seen as people. Not necessarily people with disabilities, but people in general. When seen as people, doors are opened to us. But when we're seen as people with disabilities, or people who can't do something, all of a sudden, doors are shut. (Participant)

This comment also demonstrates how sustaining disability pride is challenging when the responsibility of holding onto pride solely rests on the individual. It also reflects a common issue of conceptualizing disability as a human trait or an impairment; describing disability solely as a person's impairment problematizes the social model which frames disability as being located within the external environment and related to physical, social, and economic barriers that prevent individuals from fully participating in society. How this individual uses the word disability supports perspectives articulated by certain feminist disability scholars (see Crow, 1996; Thomas, 1999) who emphasize how impairments are also tethered to disability identity.

Certain participants also stated they were proud to be disabled. One participant reiterated how it was an inherent part of his identity and, in order to move away from feeling shame, people had a responsibility to disclose their disability: "I'm proud to be disabled. And we have to disclose that, it's important that you do that, that you disclose your disability. When we talk to people in our film, our questions also need to show that, that we want to know about disabled people's experiences" (Participant).

All of the interviews were made possible through the community connections of the participants. Building stronger connections with different people contributed to feeling a sense of community inclusion. However, the social context of how people entered into and developed these connections with different communities, specifically the level of agency one has when building these connections, played a role. The positionality of the participants as co-filmmakers, interviewers, and educators in the distribution phase influenced the quality of the connections based on the perspectives of the participants.

Screening the videos in public spaces held a similar quality where participants entered into these spaces as educators and film-collaborators while leading their advocacy efforts by sharing the videos. These roles afforded participants a level of recognition as experts in their lived experiences. Through approaching these interactions from a place of authority, the positionality of participants contributed to the quality of connections as they recognized audiences wanted to hear what they had to say:

> It really stands out what we're all about. That we educate the public and we act on it….We're saying, "Yes, we have the right to love. And we will act on it." (Participant)

The above comment reflects the importance of power arrangements in the process of sharing knowledge and how video as representative media become more than an educational tool for the community.

The history of people with developmental disabilities predominantly involves temporarily able bodied (TAB) people speaking on behalf of the disability community. However, as film-collaborators and community educators, participants drew on their own perspectives, opinions, and experiences in constructing the messaging of disability and sexuality, thus reframing the topic of sexual rights through self-representation. Another layer of self-representation also occurred within post-production. In these spaces, several participants strategized how to craft and present their final messages through their film. Part of this process involved exercising a collective capacity in defining and explaining the concepts explored through video.

The process challenges historically supported spaces where other people speak on behalf of persons with developmental disabilities (Barnes, 2007; Ramcharan, 2005). As one participant observed, the process of sharing the videos was a method of advocating on behalf of the disability community; "we're speaking out for our rights, and the rights for people like us, to fight for the right to love. It's great. I'm proud to be disabled" (Participant).

Discussion

The eugenics ideology continues to be supported in the international arena. Recent international cases have also been reported of unofficial eugenics programs applied to women with developmental disabilities being involuntarily sterilized (see Chou & Lu, 2011; Servais, Leach, Jacques, & Roussaux, 2004[7]). For instance, Servais and colleagues (2004) conducted a population-based study of 97% of women with developmental disabilities (between ages 18-46) attending government institutions in Brussels. Findings indicated that the prevalence of sterilization is three-times higher amongst women with developmental disabilities than the Belgian population. Factors that increased the probability of sterilization included being a woman and living in an institution (Servais et al., 2004). The continuing practice of sterilization, particularly women with developmental disabilities, further demonstrates the ongoing influence of eugenics ideology (Taleporos & Bowden, 2006).

Although in Canada the history of sexual sterilization acts represents discriminatory legislation representative of the eugenics movement, this research study also found that barriers

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[7] These scholars also cited Doronynsk's 1997 media article about a small, localized study of 15,000 women with developmental disabilities in Sweden and France who were sterilized.

to sexual rights are still present. At the time of this study, Alberta requires a physician to consent to a marriage involving a dependent adult, whereas Manitoba's Marriage Act section 20(2) requires a psychiatrist to "certify in writing that the party has the capacity to understand the nature of the contract of marriage and the duties and the responsibilities which it creates" in instances of persons who are dependent adults ("Marriage Act", 1987). The provinces of British Columbia, Ontario, and Prince Edward Island also deem it an offence on the part of the issuer of the marriage licence or the individual who solemnizes the marriage if they have reason to believe one of the individuals entering into the marriage has a mental disability[8]. This area warrants further investigation to address what appears to suggest provincial legislation that contradicts Article 23 in the *United Nations Convention of the Rights of Persons with Disabilities*.

This research also stresses the need to include sexual health in policy discussions about quality of life and persons with developmental disabilities where the views and opinions of persons with disabilities are at the forefront of policy discussions concerning their sexuality, sexual health, and sexual rights. The recommendations for solutions and supports as identified and presented by those who participated in this study further contribute to developing a case for practical policies and services that include acknowledgement, development, and protection of sexual rights.

Limitations

There were a number of limitations to this study, including that the participants were primarily male, White, heterosexual adults living in Western Canada. Building on the findings of this study, further research that attends to diversity of gender, age, ethnicity, and persons who identify with LGBTQ would also provide added insights into the intersection of sexuality and disability identity. As participants also discussed barriers to early, accessible sexual education and the denial of opportunities to explore their sexuality at a young age, further research into accessible education for/with/by adolescents would provide a deeper understanding of supports needed.

The approach to distribution in this study offered a strategy to reach the public through different communication channels. Participants publicly sharing their stories on video was a step toward addressing the issue of isolation faced by many persons with developmental disabilities; sharing the videos with family members also offered a way to start the conversation about sexuality; to service providers, it offered a tool to understand the need to address sexual rights for persons with developmental disabilities. Although it was beyond the scope of this research to explore the extent to which the videos impacted supports or service delivery, further research attending to this area is needed.

This study set out to explore the dimensions of sexuality from the views, experiences, and opinions of persons with developmental disabilities. Through the art of filmmaking, self-advocates also explore the challenges, barriers, and supports needed in their sexual rights. The representation of people's stories and experiences of sexual rights, coupled with the process of short individual films being developed, filmed, and edited by members of the disability community, contributes to the positionality of this research in the context of the disability rights movement and emphasizes both the need and potential for further participatory research.

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[8] See the Marriage Act of British Columbia, section 35 (1996); the Marriage Act of Ontario, section 7 (1990); and the Marriage Act of Prince Edward Island, section 23 (1988).

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