
PRAXIS WITH SELF-ADVOCATES: EXPLORING PARTICIPATORY VIDEO AS RADICAL INCREMENTALISM

KATHLEEN C. SITTER

AMY C. BURKE

Memorial University of Newfoundland

Abstract

In this article, the authors report selected findings from a larger study where self-advocates¹ from the disability rights movement created a series of short videos as part of a participatory research project. Self-advocates subsequently integrated these videos into a greater community organizing initiative with public screenings and digital methods of distribution. While the research process of this study has been published elsewhere (Sitter 2012), this piece will explore the idea of bridging participatory video, a collaborative research methodology, with community-based advocacy initiatives. The authors contend that this presents an opportunity for radical incrementalism in which to create a praxis driven predominantly by the voices on the margins versus the academic elite. In this article, a link to one of the videos is also included alongside participant reflections on the research process.

This article has three main parts: It begins by locating participatory video research within radical incrementalism. The authors then consider modes of advocacy in the disability rights movement and their relationship to social inclusion, suggesting that research should build on - and align with - the theories informing the relevant advocacy strategy. The participatory research study is then described with the intent to highlight the joining of scholarship and advocacy in the post-welfare state. Participant reflections further demonstrate how this praxis contributed to mobilizing support, developing a shared understanding of rights, and supporting collective social action.

Radical Incrementalism and Participatory Research

Radical incrementalism describes advocates pushing for fundamental change, recognizing that while change will be in the form of modest improvements at best, these gains can improve conditions for future incremental changes (Schram 101). Radical incrementalism has been used to describe Frances Fox Piven and Richard A. Cloward's strategy of combining research and activism (Schram 101). In the 1960s, Piven and Cloward worked closely with welfare rights activists in the United States. These scholars advocated the use of their crisis strategy as an ideal way for people living in poverty to accomplish a form of social justice, i.e. a national guaranteed income policy. While there is little consensus as to the factors that make advocacy successful, Bakan and Kobayashi note that Piven and Cloward are credited for encouraging scholars to recognize connections between social movements and socio-political circumstances so as to determine possible conditions for social change (53-54).

Since Piven and Cloward's work with the welfare rights movement, the idea of radical incrementalism has brought forth debates as to the strategies that best address social reform and the rates

¹ The term self-advocate is explored in the following sections, but broadly defined, it refers to persons with developmental disabilities advocating on their own behalf. In this article, participants are also referred to as "self-advocates."

of progress that are potentially achievable (Bakan and Kobayashi 53). The term “radical incrementalism” has since been applied to collaborative, community-based research approaches that strive for social change (see Shdaimah, Stahl and Schram). It calls for research grounded in community, and is based on the premise that potential accomplishments that evolve from the research may contribute to improving “the lives of the oppressed and marginalized and create conditions for...improvements in the future” (Schram 51). Schram also points to the potential of participatory research methodologies, suggesting that while activist scholars Piven and Cloward serve as one model for radical incrementalism, participatory research that is action-based is another:

It is research that is grounded in the community that takes its cues from people on the ground who are actively involved in struggle against the constraints that limit their capacity to live better. Participatory Action Research sides with these people, adopts their value orientation, seeks to work for and with these people in order to empower them to better fight the power they are challenging. Participatory Action Research seeks not to treat the people on the ground as passive objects of study but as acting subjects. (131)

Approaches to research that are participatory-based draw heavily on Freirean pedagogy, while collaboratively working with community members (Connor, Gabel, Gallagher and Morton 448). Change in this context is not necessarily characterized by large-scale alterations to policies and systems; the dynamics of the research efforts, as experienced and understood by those involved in a collaborative and action-oriented research study, are critical in developing a deeper understanding of radical incrementalism. One such example of a community-based approach grounded in praxis is participatory video.

Participatory Video

Over the last 50 years, individuals have appropriated film and video through a participatory framework to communicate a counter-hegemonic discourse that challenges mass media’s legitimization of dominant political ideologies. Participatory video (PV) is considered a participatory research method for individual, group and community organizing (White 64-66). The process involves people coming together in a group setting to develop videos about a topic or issue of concern. Through group exercises with the technology, people develop basic skills and no previous knowledge about filming is required. As community groups film reality from their perspective and subsequently share the videos in public spaces, the process enables people to become conscientized about personal and community needs, and thus has the potential to bring about social and political change (White 64-66).

History of Participatory Video

The genesis of appropriating film as a participatory method is dated back to the 1960s in Newfoundland, Canada. The socio-political context represented the welfare state period where social policy was guided by ethical liberalist ideology. The idea of a welfare state meant that government financed, organized, and delivered varying levels of healthcare, housing, education, income support, and social services (Rice and Prince 55). The history of Canadian social policy in this period “is less about sweeping reforms than about ordered change” where social policy makers proceeded with a broad conceptual framework that defined societal issues which also guided the range of government actions (Rice and Prince 66).

During this period, the Centralized Program developed by the Newfoundland Department of Welfare was succeeded by a joint federal-provincial operation entitled “The Newfoundland Resettlement Program.” By offering monetary assistance, the objective was to encourage households to relocate to growing centres as government deemed they offered more viable economic prosperity (Pitt). As a result, a number of Newfoundland communities disappeared, and many resettled workers were displaced from their traditional livelihoods of fishery (Pitt).

Fogo Island, Newfoundland, was a small island comprised of fishing communities slated for resettlement, with more than 60% of the population depending on income support (Ferreira Ramirez and Walmark 2). There were also approximately 5000 people living in 10 communities that were in relative isolation from one another (2). These communities lacked a collective voice, an effective communication channel with the government, and a forum from which their ideas could be heard and considered (Crocker 126).

Don Snowden, from Memorial University, and Colin Low, a film maker from the National Film Board, assisted the community in producing a series of short films surrounding the community's views on their life, circumstance, and economic marginalization (Ferreira Ramirez and Walmark 2-3). Creating a model for participatory video, these films were collectively produced by the communities through a cycle of filming, editing, and discussion (2-3). Once completed, the films were screened to policy makers. One of the outcomes included the people of Fogo successfully resisting government resettlement while also organizing a fishing co-operative (Crocker 66). According to Crocker, "it cannot be denied that the filming process played a large role in opening up channels of communication both among island communities and between the island and the government" (66).

As a means of challenging the resettlement policy, the people from Fogo shared what constitutes social justice from their own perspective. However, in order to contextualize efforts of social change, we must consider both the temporal and socio-political climate as well as the change focus of the respective social movement. Prior to introducing the research study, further context of the disability rights movement and the strategies guiding advocacy initiatives are provided.

The Disability Rights Movement

The disability rights movement (DRM) was founded on the transformative politics of the 1960s and was inspired by the civil rights movements around the world (Barnes 207). As a social movement, DRM is characterized as international in scope that aims at self-empowerment and consciousness-raising while also offering a critical evaluation of society, "and can be seen to focus on the quality of life of a particular section of society" (De Vlieger 1267). The DRM challenges stigmatization and marginalization of disablement by mobilizing a "sense of collective identity" through recognizing that disability is a social issue (Chivers 310-12). Premised on the social model, it is the understanding that the social and physical barriers prevent people from full participation in society (313).

In the DRM, the focus of full participation in society is closely informed by notions of citizenship (Barnes and Mercer 17; Morris). Citizenship is a set of practices (judicial, political, economic, or cultural) that define a person as a competent member of society (Turner, "Citizenship and Social Theory" 2). Turner has further differentiated between judicial and social citizenship, noting "judicial citizenship is the possession of civil and political liberties, while social citizenship is the enjoyment of the social and economic benefits of members of a nation-state" ("Citizenship and Civil Rights" 264).

The relationship between citizenship in the social realm and one's ability of full participation is critical in conceptualizing social justice: Social structures and policies that restrict or ignore the rights of disabled people often lead to discrimination and exclusion, creating disabling barriers for social citizenship (Disability Rights Promotion International). While people with disabilities may have the right to receive support and resources, the underlying values informing how these resources are distributed may be either a benefit or a disadvantage (Goodlad and Riddell 49). For instance, if framed within a charity-based model, people are often not afforded the right to define the services they need (Turmusani 6). DRM advocacy approaches associated with social citizenship are also worth considering and the extent to which these strategies focus on dismantling attitudinal and social barriers to achieve social inclusion compared to an emphasis that a person with a disability conforms to an ableist worldview.

Advocacy

Advocacy refers to "the actions taken to express one's view, to further a cause or belief, and/or to exercise rights" (Colon, Keys, and McDonald 42). Different models of disability guide different advocacy

foci and approaches toward social action (Colon et al.) where persons with disabilities, temporarily able-bodied persons and/or allies also take on different roles in the process. For persons with developmental disabilities, the two prominent approaches are citizen advocacy and self-advocacy. Each approach originated from different ideological positions. As this participatory research study discussed in this article focuses on the advocates with developmental disabilities, the following sections explore the history, characteristics, and rationale behind these two approaches.

Citizen Advocacy

Citizen advocacy focuses on allies taking leadership roles in supporting people with disabilities (Walmsley 24-28). Developed by Wolfensberger, the guiding principles include one-on-one relationships where a citizen advocate is in a volunteer capacity and is partnered with a person with a developmental disability who is referred to as “the protégé” (Flynn 30). Citizen advocacy “highlights the need for advocates genuinely to understand and represent the interests and views of the represented person, and acknowledges that achieving change can be a long-term process” (Flynn 30-31).

Along with self-advocacy, citizen advocacy, which played a role in supporting the independent living movement, was instrumental in the deinstitutionalization of people with disabilities in Western societies, and continues to have a prominent role among parents and family members advocating on behalf of their children with disabilities (Flynn 30-31).

Citizen advocacy evolved out of normalization, later referred to as Social Role Valorization (SRV) (Walmsley 26). SRV represents temporarily able-bodied people advocating for improvements for people with disabilities, where the focus is primarily to reverse the consequences of social devaluation. However, the theoretical foundation of SRV is problematic when considering the overall focus of the DRM: from a SRV position, people with disabilities are encouraged to conform to an ableist worldview in order to achieve acceptance from a society. It also places the responsibility on persons with disabilities to adapt to society in being asked to strive toward a potentially unachievable way of being.

Another concern with citizen advocacy involves the historical role of temporarily able-bodied individuals making choices and decisions on behalf of people with disabilities. Scotch and Schriener further explain this concern:

Many people have challenged the legitimacy of political representation by anyone but those who themselves have disabilities. These advocates question whose interests actually are advanced by nondisabled service providers and contend that only people with disabilities should speak on their own behalf. Such issues of representation have been applied to parents or other family members of disabled individuals. (1271)

These scholars contend that citizen advocacy is wedded to a charity-based approach toward disability advocacy, which has resulted in histories of persons with disabilities being excluded from discussions that impact their lives.

Self-Advocacy and Participatory Research

There is an affinity in participatory and action-based methodologies building on and aligning with self-advocacy. Whereas research from a post-positivist framework privileges researcher’s knowledge and expertise, participatory and inclusive methodologies value participant’s knowledge while recognizing that they are experts in their own lives (Mmatti 15). According to Mmatti, “as a matter of human rights, social justice, and respect for human dignity, persons with disabilities ought to participate in processes that shape their lives” (17).

Recent studies have explored participatory approaches that combine the use of video in disability research (Ignagni; Okahashi; Sitter). Video provides opportunities for the outcomes of the research to be accessed in non-academic spaces. For instance, Ignagni described the participatory video documentary *The Freedom Tour*, directed by self-advocates that documents “the struggle to end the institutionalization

of persons with developmental disabilities” in Canada (“The Freedom Tour” 67). Ignagni’s rich analysis of the filming process considers how participatory video can facilitate social action within the broader community (68-70).

Participatory video also holds the potential to combine self-advocacy efforts with research, where persons with disabilities are actively involved in the research process. In considering participatory video as a form of radical incrementalism, the authors report on a version of a 12-month participatory research study where adults with developmental disabilities collaboratively developed a series of short videos to explore the topic of sexual health as a human rights issue and subsequently shared the videos as part of a broader advocacy campaign.

Research Study: The Right to Love

In Western societies, people with disabilities are often perceived as asexual (Hingsburger and Tough). Crawford and Ostrove (182) emphasize that individuals with disabilities often lack resources, information, services, and support in areas of developing and maintaining positive, healthy relationships. Research studies have found that high rates of poverty, segregated institutions, silent histories, cultural values, and social stereotypes have a critical role in sustaining barriers to sexual rights for adults with developmental disabilities (Gill; Kelly, Crowley, and Hamilton; Pan and Ye; Richards, Miodrag, and Watson; World Health Organization). Findings in a Canadian research study about healthy sexuality for people with developmental disabilities stress the need for self-advocacy strategies in the area of sexual health, especially as it relates to education, support and acceptance (Hingsburger and Tough).

The Right to Love Advocacy Group

In response to these growing concerns, a group of adults with developmental disabilities in Western Canada formed an advocacy group in partnership with two community organizations: a sexual health resource center and a local organization that provides support to the disability community to develop solutions around personal and social justice issues that impact their lives.

This collaborative initiative, entitled “The Right to Love” involves working toward healthy sexuality with the goal to create an environment that supports the rights of people with developmental disabilities to develop positive sexual lives and intimate relationships. Similar to the approach advocated by Hingsburger and Tough (2002), the Right to Love group aims at challenging pejorative attitudes about sexuality and people with developmental disabilities. The group hopes their work will educate publics and raise awareness about the connections between healthy sexuality and quality of life while highlighting the need for further support services regarding the sexual health for people with developmental disabilities.

Background

One of the co-authors of this article had worked alongside the local organization for persons with developmental disabilities in several video projects. There was an interest in using video to mobilize support and educate publics on the dimensions of sexual rights. Therefore, a main goal was to engage with video as an advocacy tool in a collaborative approach. This was conceptualized through one of the guiding research questions that involved exploring participatory video as a form of radical incrementalism in the context of advocacy. The Institutional Review Board from the local university granted ethical approval and written consent was subsequently received by participants.

Theoretical Framework

The theories informing this participatory video research project included the International Classification of Functioning, Disability and Health (ICF), Freirean pedagogy and critical disability theory. The ICF defines disability as “the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers he/she may face” (qtd. in Mulcahy). This definition holds a strong approach to the social model and also acknowledges the personal experiences in

disablement. Freirean theory stresses the role of raising critical consciousness through community-led learning and praxis (Fleuri 103-11; Wallerstein and Duran 27-52). Critical disability theory is “a theoretical framework for the study and analysis of disability issues” (Hosking 1). As a member of the critical theory family that merges both critical legal studies and critical theory (Pothier and Devlin), critical disability theory represents an integrated approach to critiquing disabling structures to achieve social, political and economic change (Meekosha and Shuttleworth 49).

Process

A total of nine adults with developmental disabilities and three allies involved in the advocacy group participated. Data collection occurred over 12-months that involved 2-hour meetings approximately every other week for 4 months, and monthly meetings during the initial stages of distributing the videos as part of the larger Right to Love campaign. Filming occurred outside of these meetings. Over this 12 month period, the research process involved self-advocates co-creating 14 short videos (5-7 minutes in length) about the dimensions of sexual rights as experienced and understood by people with developmental disabilities. Emergent themes included barriers to sexual rights, needed supports, and silenced histories. The participants subsequently incorporated their videos into their larger advocacy campaign. The following is one of the participatory videos created in the research study by self-advocates, entitled “The Right to Love Group” (Disability Action Hall).²

<http://ow.ly/L1PrH>

As film-collaborators and community educators, participants drew on their own opinions, knowledge, and experiences in constructing the messaging of disability and sexual health. The following sections highlight excerpts from the research process as well as reflections from the participants regarding their experiences of being part of the study, where participant reflections further demonstrate how this praxis contributed to mobilizing support through dialogue, developing a shared understanding of rights, and supporting collective social action amongst self-advocates.

Mobilizing Support Through Dialogue

Several participants indicated that watching the interviews during editing also solidified a shared understanding of some of the issues. For instance, in one video, a participant states that he hopes 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 within the group, another participant commented that this story resonated with him on a number of levels: “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” (Participant).

While participants viewing video clips during the editing process also served to strengthen connections within the group, the act of collaborative distribution presented opportunities to create new connection with others, “by distributing our films, and working together, our voices become louder and stronger. We’re also developing relationships with others in and outside our group” (Participant). Self-advocates also thought the videos acted as a catalyst to mobilize greater support:

I see the potential in a greater way to approach our other issues. Problems are often kept internal in our community. Getting it out there to the larger community to understand it, for the government to listen, to help us, because now it becomes larger than a couple of complaints. (Participant)

² As the videos can be accessed publically, the names of the participants have been removed from this article.

Judkins' research about intergroup dialogue indicates the possibility of dialogue leading to "social action that builds a strong sense of community and an avenue toward more just and equitable structures" (33). Similar to Judkins' claim that intergroup dialogue can be an effective approach to educating people about "the individual and systemic factors of discrimination, inequality and oppression" (34), the process of screening participatory videos that highlight the barriers to sexual rights - and the supports needed to address these barriers, as defined by the self-advocates - opened up a pathway to critical discussions with a variety of publics:

Working together, we become a stronger voice. And distributing our video makes it accessible for people to know about our histories. Our problems are often kept internal to our community. Using film gets it out to the larger community. (Participant)

This comment further reflects the importance of power arrangements in the advocacy process, where public screenings also afforded participants a level of recognition as experts in their lived experiences.

Shared Understanding of Rights

Behind the camera during post-production, participants strategized how to craft and present their final messages through a visual medium. Part of this process involved exercising a collective capacity in defining and explaining the concepts explored through video. For instance, during one editing session, participants thought it imperative that the films include the vision statement of "The Right to Love" and a list of 10 core messages created by the group:

Participant 1: This list is 10 messages from everyone. We're the ones saying we have the right to love, to have children, the right to make mistakes. We define the parameters of what "rights" mean.

Participant 2: And the mission and vision statement we made as a group fits into why we're going to film. It says: "we want [our city] to be a place where everyone can have the right to love."

Participant 3: This film is a vision about human rights of disabled people's rights to love.

Participant 1: And film's a great tool to spread the word. I think we can be as radical as we want. But we want the world to know. We talk about: "let's get love out of the classroom and onto the streets where it happens."

Participant 3: That's right! Education! Education!

Participant 1: It's getting people revved up! Not being ashamed and not being told "no."

While in the end, participatory video provided a medium to share key messages, the filming process also created a space where self-advocates learned from each other. As one participant states:

What I liked about filming was that it portrayed an example of the right to love of disabled people and the rights we are allowed to have... Doing the film, gives you more of an idea of the rights that we have. So, that's how it is. I learned about my rights in making these films and listening to the stories we all shared. (Participant)

Collective Action

The process of developing, editing, and sharing the videos contributed to reframing the topic of sexual rights from the perspectives of self-advocates. Self-representation through video fostered spaces both in front of and behind the camera that broke the silence of disability and sexuality as a taboo topic. Through distribution, advocates used film to honor their own voices and the voices of people from the

disability community while challenging paternalistic conceptions of disability and sexuality. The videos further represented people defining their own experiences while supporting the self-advocacy framework. As explained by one participant: “through our stories, there’s a human piece that comes out, and a lot of times that hidden by statistics, or other people’s voices” (Participant).

The *Right to Love Group* video also includes repeated emphasis of people with disabilities standing alongside other efforts from marginalized groups to secure similar rights. Such an example first appears in the opening sequence where a self-advocate in the film clearly states: “Everyone has the right to love. It doesn’t matter if you’re gay, straight, disabled, non-disabled, everyone has the right to love.” This is further reiterated throughout the video in scenes where self-advocates march in Gay and Disability Pride Parades, as well as in the final narrated sequence where a self-advocate declares the following:

This film celebrates the right to love. We believe everyone has the right to love. Whether you’re a pet owner, a person with a disability or not, gay, lesbian, bisexual, transsexual – everyone has the right to love. (Participant)

Thus the video not only reveals an awareness of other marginalizations, but also exhibits genuine solidarity across multiple groups. This form of intersectional understanding, along with the connections with other movements as demonstrated in the video, also play an essential role in the form of radical incrementalism that is at work in this movement: To make contiguous and impactful incremental change requires considerable support both from within and outside a given movement, and the multi-modal approach that the Right to Love group takes up offers an important model to that end.

Discussion

A central aspect of participatory video involves working together to co-create an environment with the group that honors and values different ways individuals come to know and experience the world. In this study, creating and distributing participant-generated videos opened up spaces that honored knowledge derived through lived experiences. There are considerations worth noting. Engagement in this form of research requires an extensive time commitment with all involved. With rapid mobile advancements and growth of digital platforms, engagement with video and visual media require minimal resources compared to five years ago. However, knowledge of collaborative and participatory approaches amongst researchers, as well as technical skills, are required, to ensure the technology does not overpower the process itself.

As a form of radical incrementalism, participatory video bridges scholarship and activism through a participatory research methodology. Arguably, participatory video also minimizes the risk of adopting a paternalistic approach to social justice: by providing community groups opportunities to appropriate communication tools such as video, these individuals are defining and communicating what constitutes social justice from their own perspective.

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