Canadian disability activists, like others worldwide, have a history of forming and operating through formal non-profit organizations. Yet the non-profit sector is under increasing pressures that make it difficult, if not impossible, to engage in advocacy efforts. Disability is also thoroughly “managed” and served in the non-profit sector by a variety of organizations that do not necessarily have political or social justice aims. Canadian disability scholars have raised alarm about the lack of new leaders emerging in this sector (Hutchison et al. 2007, Prince 2009).

This backdrop led me to explore disability organizations and youth engagement in Ottawa. I had previously done work on youth engagement in Ontario disability movements (Kelly and Carson 2012, Kelly 2013), most notably, hosting a three day event bringing young people with and without disabilities from across Ontario to Ottawa to meet new and established leaders with disabilities in 2011. That study found young people engage in multiple forms of disability activism that extend far beyond non-profit and policy realms, including creating art, participating in social media, and self-advocating on a daily basis for accommodations and inclusion. From this point, my research on Canadian disability movements evolved in two directions – one towards documenting artistic and radical disability activism that has been historically...
underreported in Canadian disability scholarship, and secondly, towards exploring what is happening in the non-profit sector to force advocacy activities into new mediums. To address this second aim, I launched the study *Disability Organizations in an Age of Uncertainty*. This study aims to contribute to scholarship on the non-profit sector, Canadian disability movements and youth engagement, below I provide sample findings in each of these areas related to the notion of uncertainty.

**Seeking Disability Organizations in Ottawa**

Definitions of disability are expanding in both the field of critical disability studies and in provincial and federal policies, such as the Accessibility for Ontarians with Disabilities Act, that now incorporate many forms of difference. “Disability” can include physical, intellectual, sensory, learning differences, as well as chronic pain and illness and mental health concerns. To reflect these expanding definitions of disability, this study identified a broad array of 82 non-profit organizations in the Ottawa-area that encompassed a range of sizes, histories, operational level and membership. Some organizations focused on a single impairment or type of disability (e.g., muscular dystrophy, cancer), while others were cross-disability organizations. Executive Directors and staff from 25 organizations were interviewed for this research. This study also included five focus groups with diverse youth with disabilities. The study incorporated a knowledge mobilization event titled “Forging Futures” for non-profit organizations and youth held at the University of Ottawa.

**Scales of Uncertainty in the Non-Profit Sector**

Some organizations have a greater desire and ability to shape or resist the broad sociopolitical factors that govern the non-profit sector in Canada than others. Social movement scholarship, especially in Canada, has incorporated the notion of “scales” to help articulate the types of activities that can take place at different levels of government (Grundy and Smith 2005, Kitchin and Wilton 2003). Organizations operating at the national scale are the most vulnerable in the present context. Even in this small study that took place over a brief time frame, one national organization closed and another was forced to amalgamate with a different group. The national organizations in this study operate with very small staff (e.g., 0.5 permanent staff, plus contracted employees) and very limited resources. One executive director from a national organization said, “I think everybody on the national level is so focused on their own [organization] staying alive.” Services and many policy discussions take place on a provincial scale in Canada, leaving national organizations to focus largely on education and awareness, activities that can be interpreted (and were perhaps originally intended) as advocacy. In recent years, the Canada Revenue Agency has quite publicly scrutinized the political activities of Canadian charities, reducing the space for the work of national non-profit organizations.

The situation is not as challenging for all the organizations in this study. Some organizations at the provincial and local level are thriving, especially those whose core audience or membership encapsulates a topical area that aligns with government priorities or whose work emphasizes service provision. Many organizations had worked hard to develop diverse
sources of funding to provide space for creativity and freedom. One organization prided itself on operating without any government grants or funding, and the Executive Director commented: "I think one of the things that strategically the organization is looking at is more around advocacy. So you know really being an organization that is investing in advocacy it's difficult to do that if you are in receipt of a lot of government funding." It must be noted, however, that the most common secondary source of funding for organizations was charitable giving through mass campaigns or telemarketing, which typically deploy narratives of disability based in pity or cure that differ substantially from the rights-based or alternative understandings that the organizations promote in their advocacy efforts, revealing a central paradox of disability organizations. I now turn to this clashing of worldviews, to explore how disability organizations actively or inadvertently define disability in a climate characterized by multiple and competing perspectives.

Clashing Perspectives: Defining Disability

Baines (2015) argues non-profit long-term care homes lack the ethos apparent in non-profit social services (an ethos that varies in strength depending on the organization). She speculates this divide might be traced to factors such as the high degree of regulation of the activities of long-term care, the minimal educational requirements that emphasize skills over knowledge for long-term care workers, and generally speaking, the underlying medical model. The rift between social and health approaches to services is strongly apparent and relevant to disability organizations. I now turn to this clashing of worldviews, to explore how disability organizations actively or inadvertently define disability in a climate characterized by multiple and competing perspectives.

Limited Roles for Youth

A diverse group of young people, aged 18-25 participated in five focus groups. They were recruited through Algonquin College and the University of Ottawa, and there was a specialized group for people with intellectual disabilities that used different recruitment tactics and visual techniques. The youth who participated in the focus groups were largely unfamiliar with most disability organizations, but seemed to be relatively well-served in the education system. For example, one youth participant said, "[...] in high school there was more of a support system. Through the Special ED learning, but then the university [was difficult] because there was so much more of a mass education. It’s harder to transition and especially in classes it's difficult to identify with the prof.”

Interestingly, even though the youth attended the focus group because they had responded to advertisement looking for “people with disabilities,” very few openly accepted this type of identification during our discussion. Many were uncomfortable with the concept of disability, and had very limited exposure to alternative understandings beyond a medical or therapeutic framework. Even more surprising was the tendency to speak about a “friend in a wheelchair” rather than experiences from their own lives. One youth participant commented, “I have a friend, well I am like acquaintances with this girl, who she is in a wheelchair … I can’t actually remember what her disability is.” Thus while the category of disability is expanding in scholarly and policy settings, this understanding is not well circulated among those who are folded in.

Discussion and Conclusion

It is clear that disability organizations are in a moment of transition in terms of political context, definitions of disability and finding roles for youth— a moment that will likely be further destabilized by the federal election. Many disability organizations find themselves in a highly precarious situation, especially those at the national scale who emphasize (or would like to emphasize) advocacy or education. Similarly, disability in the non-profit sector remains a rich ground for documenting and exploring evolving and contested meanings of disability, and the ways in which the medical/social divide set up by early disability scholars retains some relevance in understanding why the approach of one organization may differ so significantly from that of another. This distinction, however, is becoming more blurred and difficult to identify. This sector is also having a difficult time reaching out and engaging with youth in meaningful ways, despite the heavy emphasis on strategic planning and other activities that gesture towards the future. Part of this challenge is linked to
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the diverse (and divisive) definitions of disability that occupy the public imagination. Youth are often only exposed to therapeutic and individual diagnoses, and as such, it is more difficult to seek out collective or alternative understandings. Organizations who wish to promote such understandings would likely be interpreted as “political” or “advocacy” and are directly limited by the sociopolitical context governing the non-profit sector.

In a climate with more voices, more scrutiny, and narrowing funding opportunities, it can seem like disability organizations are destined to fail; yet, uncertainty also yields resilience and creativity, characteristics that were strongly apparent among the organizations and the youth participants. Indeed, the uncertainty indicates a moment of transition around our understandings and approaches to disability, the outcomes of which are yet to be seen.

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A collection of articles on this topic tentatively titled Mobilizing Metaphor: Art, culture and disability activism is under consideration at UBC Press. The collection is co-edited by Dr. Christine Kelly and Dr. Michael Orsini, Chair of the Institute of Feminist and Gender Studies and Full Professor in Political Studies at the University of Ottawa.

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