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Reconsidering Knowledge and Power: Reflections on Disability Communities and

Disability Studies in Canada

Michael J. Prince

Abstract

Reflecting on knowledge production offers imaginative ways to think about disability organizations and Disability Studies. Following Foucault, the concepts of knowledge and power are central to this discussion and in addressing these questions: what kinds of knowledge circulate in and around disability communities in Canada? How does this knowledge connect disability organizations and movements with the Canadian state and other institutions in society? What might the future hold for more creative and innovative knowledge production for disability studies, disability activism and social change? The article maintains that the politics of knowledge production are not so much about generating evidence in contrast to ignorance, as about multiple forms of knowledge interacting with, and struggling against each other within particular fields of power relationships. The marginal status of lived experience by people with disabilities is the outcome of a politics of reality, of who gets to decide what counts as evidence and who gets to decide the rules around knowledge production and dissemination.

Keywords

Knowledge production and circulation; Power relations; Canadian state; Disability activism; Ontological multiplicity

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Introduction

As a contribution to the emerging scholarly literature that examines Canada's disability movements and their many forms of activism (Chivers 2008; Enns and Neufeldt 2003; Kelly 2013; Panitch 2008; Prince 2012; Reville and Church 2012), this article explores the following questions: what kinds of knowledge circulate in and around disability organizations and movements in Canada? How does this knowledge connect disability communities with the Canadian state and other institutions in society? And, what might the future hold for more creative and critical knowledge production for disability studies, disability activism and social change?

Theoretically, I draw on the work of Foucault (2003; 2004; 2006), no stranger to researchers in Disability Studies, in considering knowledge, power and activism.¹ According to Foucault, because power originates in so many different places, its practice is not the same in each place or site. Power can be both blatant, as in a violent act of destruction, and subtle, as in a hidden act, the impact of which comes only later. There is coercion, manipulation, corruption, and malevolence as well as cooperation, persuasion, ethics, and benevolence. Never absolute in its deployment, power is always negotiable. Just as there is assertion, there is contestation; to Foucault, if there is subjugation, there is opposition; where there is oppression, there is

¹ On the presence of Foucault in Canadian Disability Studies, see Titchkosky (2003), Malacrida (2003), McColl and Jongbloed (2006) and Wither (2012). Malacrida's book (2003) is an outstanding example of a poststructural understanding of power employing Foucault, in that case, to 34 women dealing with attention deficit/hyperactivity disorder children. Another Canadian scholar with substantial published work on Foucault in regards to disability is Tremain (2005).

resistance. Being both productive and relational, Foucault's notion of power is useful in understanding how certain practices (say, psychiatry) and groups of people (psychiatrists) come to have an influence on subjugated bodies (psychiatrically troubled persons). Power is intricately woven into the production of knowledge, bodies, and subjectivities through what Foucault refers to as power/knowledge. Power/knowledge describes a specific coalescence of relations that link particular strategies of the deployment of power with a specific set of truth claims (Foucault 2004; 2006). The circulation of power and truth claims is not uniform. Because power is productive, expressions of power are never identical (but can be similar), always local (but never localized), and inevitably unstable (though fixed enough to generate effects). Because power is relational, what matters are the arrangements of force relations and how people experience those relationships. Tracing these arrangement or techniques can show how specific bodies are effects of the circulation of power and knowledge.

The main arguments of this article can be summarized in three statements. Firstly, the Canadian disability community actually comprises several communities or arenas of social action, each of which has been examined by one or other social science and humanities discipline. The overall community is a diverse sector of service organizations (Bach 2002; Levesque 2012), a policy community of interest groups and coalitions (Boyce, Tremblay, McColl, Bickenbach, Crichton, Andrews, Gerein, and D'Aubin. 2001), a comparatively new social movement (Chivers 2008), multiple movements that include radical, do-it-yourself, and creative forms of activism (Kelly 2013), a constitutional category of citizens under the Canadian Charter of Rights and Freedoms (Devlin and Pothier 2006), a domestic community of organizations and activists that extends abroad with various international activities and connections organizationally (Enns and Neufeldt 2003; Prince 1992), and a research and

knowledge production network (Prince 2009). As a consequence, divergent perspectives on ability/disablement, politics and possibilities circulate within the community, the state and wider society.

Disability, knowledge and power are characterized by a multiplicity of discourses, in varying kinds of complementary and contradictory relations. In the Canadian context, these discourses include: charitable paternalism (Valentine and Vickers 1996), inclusive and empowering communities (Lord and Hutchison 2007), citizenship and equality rights (Chivers 2008; Prince 2009; Stienstra and Wight-Felske 2003) a spiritual humanitarianism (Vanier 1998), practices of medical expertise and associated struggles (Moss and Teghtsoonian 2008; Tremblay, Campbell and Hudson 2005), including antipsychiatry and mental health survivor critiques (Shimrat 1997; LeFrançois, Menzies, and Reaume 2013), welfare and warfare statism (Strong-Boag 2007), forbidden, unfitting and testimonial narratives (Church 1995; Dossa 2008; Raoul, Canam, Henderson, and Paterson 2007), experiential stories (Crooks 2007; Driedger and Owen 2008; Krause 2005) versus official rhetoric (Levesque and Graefe 2013; Poole 2011), discourses of motherhood and by mothers (Malacrida 2003; Panitch 2007) and the effects of systemic oppression (Devlin and Pothier 2006; McCreath 2011; Reaume 2000; Withers 2012).

Secondly, governments have at their disposal numerous practices and techniques that structure social relations, modify the status of groups, and affect their quality of life (Prince 2009; Stienstra 2012). In an assortment of ways and for a variety of reasons, political and bureaucratic officials engage in structuring the production, dissemination, suppression and regulation of information, research and evidence. Recognizing the operation of such power dynamics is crucial to a critical study of disability and to a creative rethinking of knowledge and power relations.

Thirdly, thinking of the disability community as a knowledge production network raises implications that should figure in decisions about future research directions and funded projects. Disability Studies must embrace a conception of power and knowledge that recognizes both negative and productive effects, and that takes into account the full range of governing mechanisms and policy instruments at play in state and civil institutions. Recognition of both continuities and disjunctures in the exercise of authority enhances the possibilities for resistance and social change.

Disability and Knowledge Circulation, Production, and Contestation

The Canadian disability community consists of multiple, distinct, and often divergent arenas: interacting sets of individuals, organizations, ideas, interests, and processes engaged in social actions, some contradictory, some complementary, which affect disability and public understandings of disability. The social production of knowledge features in all these facets of the community, whether that knowledge supports service provision and administration, litigation or tribunal hearings, government lobbying, or artistic and cultural politics.

Personal interactions with disability service agencies in local communities, under the auspices of charities and their public sector counterparts, provide a growing body of critical autobiography, oral history, and other narrative forms by people living with disabilities. This can involve a shared production of knowledge on disability between the editor/researcher and the narrator/storyteller (Church 1995; Crooks 2007; Krause 2005; Moss and Dyck 2002; Raoul et al. 2007; Tremblay et al. 2005). Such narratives connect the private and public domains of a person's life, and cast light on coping and the healing, as well as controlling, provided by community services and by peers and families.

In this neo-liberal age, many social care and human service agencies are undergoing deliberate changes to adopt new values and innovative approaches, shifting from an ethic of benevolence and compassion towards a philosophy of self-determination and person-centred supports. Examples of national consumer-driven disability organizations controlled mainly by people with disabilities are the Alliance for Equality of Blind Canadians, Council of Canadians with Disabilities, People First of Canada, National Network on Mental Health, and the Canadian Association of Independent Living Centres. In this regard, Lord and Hutchison (2007) distinguish between service agencies with a traditional approach that emphasizes 'client hood' and 'victimhood' among families and individuals living with disabilities, and a new approach, at least for those agencies, which promotes 'personal choice,' quintessential language of neoliberalism joined with aspirations of self-determination. Talk of individualism and consumers' rights may well promote beliefs in personal experience and human agency and celebrate self-governing citizens; but, neoliberalism also individualizes responsibility and downplays structural determinants of living conditions. In valorizing local agency, systemic inequalities in power are ignored and there is always the risk of important health and social provisions being retrenched or privatized in the name of empowering individuals and families or of promoting recovery (LeFrancois, Menzies, and Reaume 2013; Rice and Prince 2013).

Christine Kelly (2013) usefully points out that the parameters of the Canadian disability movement go beyond organizations in the non-profit and service provision sectors to include other forms of activism that are radical, creative, online, do-it-yourself, and third-wave feminist. The multiple disability movements embrace artistic, disability pride, mad pride, survivor, visual, and youth styles of engagement (LeFrançois, Menzies, and Reaume 2013; Reville and Church 2012; Shimrat 1997; Wither 2012). Many of these disability movements employ confrontational

techniques and do not focus particularly on the state nor necessarily adopt a "social liberal" political outlook, some expressing instead a hard-hitting anti-capitalist position (Kelly 2013: 13, 16).

Canadian colleges and universities are another site of growing significance for the production, reformulation and circulation of different forms of knowledge, notably through disability courses and Disability Studies programs of study. One example is the development of Mad Studies at Ryerson, Toronto and York (LeFrançois, Menzies, and Reaume 2013). Disability studies scholars and students are producing, critiquing, and disseminating artistic, comparative, historical, and theoretical forms of knowledge on disability and normalcy. Academe evaluates policies and practices as well as assists in bringing to wider audiences the narratives of people and communities, at times joining community-based activism and academic-based research. When done in a mutually respectful and accountable manner, such research can enlighten and empower both academics and community members (Stienstra 2012). When done imaginatively, such work shifts the boundaries between private and public domains, making personal troubles into policy issues, drawing attention to inclusion/exclusion, interrogating conventional models and practices, attacking oppression, and advancing citizenship.

Policy-related disability research considers public policy development and program delivery; and examines the effects of policies and programs on the social environments, life transitions, and opportunity structures of persons with disabilities. Policy-related disability research also critically assesses conceptions of disability contained in laws and social practices. Intended to be usable by policy makers and practitioners, such research may serve any number of purposes: the definition and understanding of an issue; the more effective response to and management of a need or problem; the resolution or alleviation of a problem or need. In addition

to the identification of additional lines of inquiry, policy-related disability research, when done in a respectful way, enables the expression of voice by a group and the recognition of their experiences, and thus the empowerment of a group through that research process.

Within federal, provincial and territorial governments are departments, agencies, advisory councils, and research groups involved in policy-related disability research, some of which is directed at international activities and organizations. In our imperfect system of citizen participation and public accountability, legislative committees in provinces and the federal level can be significant political institutions for disability groups and disability policy. In recent years, offices of parliament and legislatures, most notably auditors general and children advocates, have conducted reviews of developmental disability services, family support services, social assistance programs and mental health services. These sorts of reports serve several useful functions for disability policy research and analysis, as well as for the wider disability community. If done well, such reports, which tend to be viewed by the media and the public as independent and expert studies, can be effective in raising and debating issues, engaging with groups in public forums, gathering information, reviewing legislation and considering bills. By scrutinizing government performance and recommending policy developments and program or administrative reforms, such reports have a potentially important action dimension as well (Boyce et al 2001; Chivers 2008; McColl and Jongbloed 2006; Valentine and Vickers 1996).

Multiple and divergent perspectives on disability circulate in Canada's policy research community. One perspective, a social model of disability (and variations on that model) appears in the work of the Council of Canadians with Disabilities, Canadian Centre on Disability Studies, Caledon Institute of Social Policy, and university programs such as the Ryerson RBC Institute for Disability Studies Research and Education. This social orientation, well rehearsed and

debated in the literature (Oliver and Barnes 2012; Rioux and Valentine 2006; Withers 2012), emphasizes the values of equality rights and full citizenship, and usually employs a critical analysis for studying social structures and public policies (see, for example, Devlin and Pothier 2006). Another perspective prominent in disability research deals with functional impairments, rehabilitation, and integration. Disability management and rehabilitation therapy programs at certain universities reflect this perspective. So, too, do particular research centres on children and health services. In this orientation, people with disabilities commonly appear as individuals with special needs, facing possible risks, with official identities as program clients and care recipients.

Populating the disability policy communities in Canada are countless associations of different kinds and at different geographical scales. On behalf of a cluster of interest groups or service agencies, associations may represent a particular disability, a distinct client group (based for example on age, ethnicity, sexual orientation, and locality), a specific provincial or regional area, or a functional activity such as legal advocacy. The overall community differentiates significantly by political perspectives, movement tactics, social issues, and organizational resources and structures. A number of umbrella associations – at national, provincial/territorial, and urban levels - represent the relevant interests of a constellation of groups. Instances are the Canadian Association of the Deaf, the Canadian Hard of Hearing Association, the Canadian Association for Community Living, the Canadian Association of Muslims with Disabilities, the Manitoba League of Persons with Disabilities, the Ethno-Racial People with Disabilities Coalition of Ontario, and the Action des femmes handicapées in Montreal. Taken as a whole, both disability movements and Canadian federal and provincial states contain various perspectives on disablement, some of which are in sharp tension or conflict with one another (Bickenbach 1993; Devlin and Pothier 2006; Titchkosky 2003a).

The Canadian State as a Site of Knowledge/Power

On the whole, Disability Studies as a field of academic inquiry characterizes public power (state authority) as exercised in a top-down manner, having negative consequences for marginalized people (Charlton 1998; Devlin and Pothier 2006).

Krogh and Johnson (2006), for example, examined the power relations between home support administrators and users living with impairments in British Columbia. Through home support policy rules and assessment procedures, the personal needs of potential clients were rigidly defined and dependency notions of disability were constructed, constraining the actions of individuals and families within this particular field of social service. According to Krogh and Johnson: "When disabled people defy the notion that disability involves dependency, they are subjected to disciplinary power or consequences through the denial of adequate home support service and, even when they are deemed worthy of home support service, they remain the objects of surveillance. When they attempt to access services such as home care within a welfare framework, people with disabilities are expected to give up their right to freedom from interference and their right to privacy" (2006: 161). They add that: "Removal of home support is a powerful force that operates to constrict the individual and collective voice, circumvent resistance, and limit opportunities for our society to benefit from contributions from all its members" (2006: 173). This negative of view of power is unsurprising given the dark history for many people with disabilities with asylums, electroshock treatment, and sexual sterilization laws and practices; and, the still troubled conditions of most people with disabilities with segregated classrooms, sheltered workshops, a life of low-income poverty, and exclusionary immigration rules (McCreath 2011; Withers 2012). In relation to disabled people, this exercise of power has

the harmful effects of diminishing personhood, ignoring fundamental freedoms and rights, producing absences and reproducing exclusions.

In this representation, the core mechanism of power is regulatory - whether delivered in the form of an income benefit or a service program - with intense coercive aspects and punitive results. In provincial social assistance, the single most important income program for lowincome people living with disabilities, the experience involves a maze of rules and controls: long and complex application forms, medical documentation, narrow eligibility definitions of disability, limitations on assets and savings, rules about living arrangements, the denial of benefits for many claimants, a convoluted appeal mechanism; and, if successful, after all that, an inadequate level of financial assistance that means a life of poverty and dependency on the kindness of friends and strangers (Withers 2012). In a study of mothers of children with attention deficit disorder or attention deficit hyperactivity disorder, Claudia Malacrida showed how mothers are "incorporated into 'partnership' with professionals in the moral and social regulation of their children" (2003: 228). Malacrida writes of "maternal concerns for the immediate outcome: if one does not play according to the rules, one will not continue to be considered part of the team, and the encounter will go badly from the start. A more long-range concern is that if one does not cooperate, the proper referral to the next rung on the ladder will not be made. Finally, if one does not cooperate with professionals, there is always the risk that the underlying suspicion – that the troubled child's problems stem from family pathology – will be shored up because the mother has shown herself from the outset to be non-compliant in dealing with helping professionals" (2003: 230). In disability activism, these distressing features of power relations are probably most recognized by radical and survivor activism (Reville and Church

2012) and those seeking to create alternative and de-medicalized spaces for everyday living (Dossa 2008; Malacrida 2003).

At times, power is additionally conceptualized in more positive terms, laying emphasis on personal agency, resistance and the possibilities for organizing and mobilizing for social change. Though not all, many Canadian disability groups look to federal and provincial governments, along with city governments, as defenders of human rights, providers of public services, and enablers of social inclusion (McCreath 2011; Prince 2012; Stienstra 2012). The potential of public power is seen in offering affirmative recognition and protection of differences; dismantling barriers and building up supports and services; and shifting public attitudes more favourably toward issues of accessibility, disability and inclusion. In this context, a range governing instruments are targeted by disability movement groups: legislative powers, for sure, as in accessibility and human rights laws as well as program expenditures, personal tax income and retail sales tax measures, myriad public programs and community delivery systems, information services and symbolic resources of recognition.

For disabled people and disability organizations, the effects of power can seem all pervasive and unyielding in cultural, economic or environmental terms. However, the deployment of power by the state or other major institutions in society is not always comprehensive and uniform in the way it is exercised. This is because of the history of fragmented program developments which reflects, in part, the range of recognized and contested diagnoses and impairments (Moss and Teghtsoonian 2008; Withers 2012); because of the division of legislative powers between federal and provincial orders of government (Levesque and Graefe 2013; Rice and Prince 2013; Stienstra 2012); because of shared responsibility among the sectors of society for disability; and, because of the periodic retrenchment of services and the

intermittent reorganization of delivery systems (Bach 2002; Lord and Hutchison 2007). Results involve a fragmentation of knowledges across organizational silos and program systems as well as discontinuities and inequalities in relations of power.

In regards to knowledge on and of disability, state institutions in Canada exercise several methods of manufacturing and managing knowledge. These techniques include the following:

The production of data and the dissemination of information through various social surveys and related articles and reports, typically conducted by Statistics Canada, the national data collection and dissemination agency. Since the late 1980s, Statistics Canada has undertaken national surveys of people with disabilities, an initiative widely endorsed by Canadian disability organizations. These social surveys, the latest version of which is called the Canadian Disability Survey (Statistics Canada 2013)², yield information on the lives of youth and adults with disabilities and, in comparing their circumstances to Canadians without disabilities, document the depth of their precarious citizenship. Other administrative data sets reside in provincial workers' compensation systems, corporate insurance schemes, and health care facilities, much of it inaccessible or rarely made available to the public. Government data are also created via contracted work to academics, think tanks and consultants, although such information is not usually publicly available. Therefore, the field of documentation on the barriers faced by people with disabilities, as well as on their strengths and aspirations, is stratified into layers of visible and invisible knowledge. These government-generated forms of knowledge construct individuals as cases or data points and into groups as categories; as measurable objects of general phenomena against statistical norms.

² The Canadian Survey on Disability (Statistics Canada 2013) was conducted in 2012 and results began being published in 2013 on type and severity of disability, use of aids and assistive devices, help received or required, educational attainment, labour force status, experiences and accommodations at school or work, and ability to get around the community.

Suppression of information sharing and of knowledge generation and contestation by means of official rules and bureaucratic practices of widespread secrecy and confidentiality or inaccessibility. Failure to provide information in accessible formats and in plain language effectively stifles a straightforward giving out of knowledge relevant to citizens. Other state activities have suppressive effects that can result in the erasure of disabled people. These tactics include the reluctance or outright refusal by officials (usually because of dictates from political superiors) to engage in meaningful consultations with community groups; retrenchment in funding to groups to be able to participate in such consultations; and, the cancellation of the Court Challenges Program [which the new Liberal government of Justin Trudeau, elected in late 2015, is committed to reinstating], that assisted groups to intervene in strategic cases dealing with equality rights under the Canadian Charter of Rights and Freedoms (Prince 2009). These tactics are a mobilization of bias in politics with direct consequences for the way issues are defined and priorities established and by whom. Individuals with impairments living in a disabling society are constituted as program applicants and clients in various conditions of need, rather than as citizens with constitutional rights seeking equality and equity.

Hierarchical classification of knowledge by some scale of evidence-base, scientific rigor and prevailing notions of legitimacy. Typically, stories or narratives from individuals or families are at the low end of the dominant hierarchy of credible evidence (Malacrida 2003), followed by the opinions of stakeholder groups, evidence from a qualitative study, then evidence from a welldesigned quantitative analysis, perhaps followed by a precise control trial or cohort study, and then a randomized controlled trial, culminating with a meta-analysis of all applicable evidencebased studies on a topic, group or program. While such hierarchical ordering of information and knowledge is not new, today evidence-based practice is a major trend in medicine and nursing

and other areas of clinical work as well as infusing many areas of social policy and practice. One effect of this ordering of knowledge is to eliminate and disqualify as insufficient or unproven "what people know at a local level" (Foucault 2003: 8). What occurs is a disassociation of knowledge from the lived experience of everyday existence. Experiential knowledge is converted or some might say, perverted into aggregates of data and generalized narratives for purposes of state administration and officially-styled discourses. The marginal status of lived experience by people with disabilities is not an inevitable result of scientific rationality but the outcome of a politics of reality, of what Foucault called truth games (Foucault 2004 and 2006); that is, who gets to decide what counts as evidence and who gets to decide the rules around knowledge production and dissemination.

Regulation of information production and circulation by civil society organizations, in particular registered charities. Tax rules administered by the Canada Revenue Agency on which organizations qualify for registration as a charity and thus eligible to charitable donation tax credits are a thorny issue for the voluntary sector, including disability rights organizations. As Susan Phillips explains: "The determination of status as a charity is important because it enables such organizations to have potentially greater access to resources by providing incentives to give (on both an annual basis and through estate planning), but it is also an important indicator of legitimacy" (Phillips 2006: 130). Indeed, through intensified audits by tax officials and critical political discourse by government members, Conservative federal governments under Stephen Harper tightened such charitable tax status restrictions, certainly with respect to environmental non-profit organizations and other progressive charities. Creating a chilly climate for public policy advocacy was the intended effect, again subjugating the richness of biographical accounts of oppression and subduing the radical nature of social justice claims.

Cooptation or annexation of innovative ideas and critical discourses from community groups and movement organizations into traditional state discourses and ways to thinking. This may optimistically be viewed as a way of renewing a bureaucracy, although it is more frequently interpreted as a classic tactic by government bodies to neutralize perceived threats and to manage challenges from outside groups. Disability studies scholars and activists alike recognize these dangers of appropriation for the disabled people's movement and groups regularly struggle with such risks of collaboration with government officials (Boyce et al. 2001). Barnes and Oliver express the risks involved in disability activists and groups participating in conventional politics: "To get too close to the Government is to risk incorporation and end up carrying out their proposals rather than ours. To move too far away is to risk marginalization and eventual demise. To collaborate too eagerly with the organizations for disabled people risks having our agendas taken over by them, and having them presented both to us and to politicians as theirs. To remain aloof risks appearing unrealistic and/or unreasonable, and denies possible access to much needed resources" (1995: 115). Disability movement organizations with a radical orientation typically seek to avoid these risks by not engaging directly with the state officials in any case, preferring more confrontational forms of activism (Kelly 2013). Organizational and social movement tactics, then, are both effect and object of state power and knowledge.

Running through these five techniques of manufacturing and managing knowledge is an image of top-down relations of power. Certainly, the subjugation of certain popular ways of knowing is one of the hallmarks of privilege. Yet even in these situations of apparently unequal power relations there are potential spaces of resistance and strategic tactics. Wherever state-civil society relations are at work, interpretation and discretion are present in specific forms, spread in uneven ways over time and space, operating in some manner beyond the grasp or gaze of

authorities. In any social hierarchy there is human agency with multiple points of local opposition within formal organizations and institutions. Because power is rarely practiced *on* someone, the subject (as knower and the object as known) becomes the effect of the circulation of multiple, and competing, configurations of power/knowledge. One example is the tension between evidence-based practice and embodied health movements (Brown et al. 2004), in which social movement groups challenge undue reliance on certain scientific accounts and established medical practices. The multiplicity of perspectives on disability – charitable, community-based, humanist/spiritual, medical, rights-focused, social welfare administration – compete and conflict. They conflict because of their different origins and contending ideas; their separate institutional arrangements and often dissimilar interests; and their different objects of analysis and targets of intervention or non-intervention. Thus, knowledge of disability occurs in numerous ways of manufacturing, managing and manoeuvring data, information and discourse.

The politics of knowledge production are not so much about generating evidence in contrast to ignorance, as about multiple forms of knowledge interacting with, and struggling against each other within particular fields of power relationships. Power resources and power effects are rarely distributed evenly. Different interests have distinctive capacities to act, and they articulate diverse ideas and contrasting views of what priorities should be in disability in regards to identities, rights or services. Each viewpoint produces particular power outcomes. Consequently, there are patterns of power *over* (domination), power *with* (collaboration or partnerships), and power *to* (the capability to do or influence something). At times, the structures and processes of power relations may be experienced as non-zero-sum, whereby all participants feel their voice is respectfully heard and their interests have been substantively advanced. More

frequently, however, relations of power come across as zero-sum relationships of starkly forced trade-offs and significantly unequal policy outcomes.

Future Directions for Disability Studies

As an academic field of inquiry in Canada, studying disability is coming of age. In 2004, a network of Canadian researchers, advocates, academics, and policy officials formed the Disability Studies Association/Association Canadienne des Études sur L'Incapacité. In 2011, the Canadian Journal of Disability Studies was established and the first issue arrived in 2012. Important books in Canadian disability studies have appeared in recent years, including works on imprisonment and disability in Canada and the United States (Ben-Moshe, Chapman, and Carey 2014), the treatment of disability in Canadian fiction (Brenna 2015), disabled women (Driedger 2010), (the politics of blindness (McCreath 2011), mental health recovery (Poole 2011), critical theory and policy and practice (Robertson and Larson 2016), disability rights monitoring in Canada and internationally (Rioux, Pinto and Parekh 2015), disability rights (Stienstra 2012), issues of space and access (Titchkosky 2011), disability politics and theory (Withers 2012), and Mad Studies (Shimrat 1997; Reaume 2000; LeFrançois, Menzies, and Reaume 2013). Mad Studies, as LeFrançois, Menzies, and Reaume (2013: 337) explain "embrace[s] the body of knowledge that has emerged from psychiatric survivors, Mad-identified people, antipsychiatry academic sand activists, critical psychiatrists, and radial therapists." This growing and reclaimed body of knowledge "is critical of the mental health system" while generally approving of the psychiatric consumer, survivor and ex-patient (c/s/x) movements.

A promising part of the future of disability studies lies in remembering the past and in recovering historical knowledge as, for example, with the Psychiatric Survivor Archives of Toronto. Written records in the archives and file boxes of disability organizations are a valuable source of knowledge that offers insights. Histories of disability activism are much more than just describing bygone events or recalling forgotten actors, though these are important undertakings for any social movement. Documenting, writing up, and celebrating disability histories create shared vocabularies and collective memories; a knowledge of struggles and tactics, of setbacks and achievements in services, equal rights and inclusion (Panitch 2007; Reaume 2000 and 2012; Stienstra Wight-Felske 2003; Strong-Boag 2007; Tremblay, Campbell and Hudson 2005). Persons with disabilities emerge as knowing subjects, as human actors with capacity. As a shared knowledge of struggles and successes, disability history can be deployed as a strategic resource within contemporary contexts of policy to inform movement tactics and to possibly modify social relationships and practices (Chivers 2008; Foucault 2003; McKenzie and Wharf 2015). Such historical knowledge can also serve as a cautionary tale in regards to claims of major shifts in societal beliefs and practices - whether actual or aspirational - from the asylum to independent living (Boyce et al 2001); from charity to parity (McCreath 2011); from stigma to identity politics (Anspach 1979); or from paternalism to rights (Valentine and Vickers 1996). The material and discursive particulars of any such claims of social progress must be carefully and concretely probed

Disability is a social field that contains contending forms of knowledge and agendas of action and inaction. Some ideas and information on disability are organized into public debate and policy making while other ideas and information are organized out of official politics. Thinking of the disability community as a knowledge production network locate within a larger

political economy of truth claims raises implications that ought to figure in decisions about research directions and funded projects.³ One such consideration centres on attracting organizations into this research community that previously have not been involved, thereby adding new players to the network, such as groups that represent employers, professionals, seniors, or unions. A second is the possibility of using research in the humanities and social sciences for fostering partnerships among organizations in the community and/or with actors in a related policy realm. Third is leveraging resources from the foundation sector, which, in Canada, is not a major source of funding for policy institutes and think tanks.

A conception of power and knowledge that recognizes both the continuities and disjunctures in the exercise of authority offers possibilities for resistance and social change. Power relations found within disability policy and disability studies are linked to particular forms of knowledge (expert and lay), discourses or political rationalities (official or dominant and oppositional), and social structures (civic, economic, familial, gender/sex, and religious).

Disability activism as an ontological multiplicity

This article has focused on the nature of, and interplay between, knowledge and power in disability communities and Disability Studies in Canada. The purpose has been to identify and discuss kinds of knowledge that circulate in and around the contemporary disability movements. State institutions in Canada exercise a number of techniques for manufacturing and managing knowledge about disability. Associated with these techniques are certain formations of knowledge and thus certain relations and exercises of power. The techniques include producing and disseminating data that create, count and characterize disability populations; suppressing

³ From 2009 to 2014 I was Co-Principal Investigator of a Community University Research Alliance, called Disabling Poverty, Enabling Citizenship. It involved partnerships across five universities and five disability and social policy organizations. For details, see <u>http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship</u>

information and contestation via secrecy; ranking the value of different sources for, and types of knowledge on disablement; regulating the production and circulation of information by civil society organizations; and, co-opting critical ideas from community groups and converting them into more conventional state discourses and ways of thinking. It is through these techniques, as sets of social relations imbued with power, that knowledge about disability, normalcy, equality and other critical ideas come to be used, debated and challenged within society.

Among their effects, these techniques structure the relative (in)visibility, and thus political status, of groups of people with disabilities for making claims for inclusion and justifying them on knowledge grounds. Restrictive or negative effects, certainly from the perspective of disability groups, are evident in the technologies of state authority that abstract, conceal, and unduly medicalize information along with the subtle coercive risks of consultation processes and partnerships with professionals. What Foucault called productive effects of power are apparent as well. These effects include creating domains of information, establishing norms and realities, and constructing individuals and groups as subjects. From a critical disability standpoint, these productive effects of power are not obviously helpful or beneficial for people living with impairments or with mental health issues. Relations of power and their consequences are more complicated than this distinction between restrictive and productive effects would suggest.

Disability activism as a social movement is an ontological multiplicity. Working in, through and around disability organizations are competing power/knowledge configurations. Present in disability politics and policy are rival ways of thinking about disablement that are received or rejected by various policy and decision makers, professionals, community activists, self-advocates, administrators and practitioners (Mol 1999; Moss and Teghtsoonian 2008).

"Identity politics" for disabled people, according to Anspach, "is a sort of phenomenological warfare, a struggle over the social meanings attached to attributes rather than an attempt to assimilate these attributes to the dominant meaning structure" (1979: 773). The ontological politics of disability activism involves struggles over shaping what is, could be, or ought to be made more real or less real. Always there is the contention of knowledge claims, including claims of what knowledge is (including the legitimacy of lay knowledge vis-à-vis expert knowledge), regarding the cause and nature of impairments, and their effects, and the significance of social structures and practices on the capacity of persons with disabilities to participate in education, cultural, economic, and political spheres of everyday life. At the same time, a necessary and important contestation of praxis takes place through disputes over relevant strategies and effective techniques for disability activism and advocacy (Chivers 2008; Dossa 2008; McCreath 2011; Robertson and Larson 2016). Of the jumble of relationships that comprise the social world, aspects that are privileged at any given time – the political ontology of the moment – affect what opportunities exist for meaningful interactions, what issues are up for discussion, how topics are framed discussively and materially, and what interventions are on hand. These struggles are unmistakable when activists and community organizations come up against established biomedical paradigms and clinical practices, and confront entrenched bureaucratic understandings of what constitutes disability for the purposes of economic and social programs.

The discussion presented here and in recent works on Canadian disability movements (Kelly 2013; Reville and Church 2012) point toward possible directions for future work.

Thinking of disability movements in terms of numerous material discourses and several configurations of knowledge/power, suggests the presence of discrepancies and disconnections

as well as similarities and linkages. How do such connections and tensions emerge and play out in disability activism? What are the advantages and drawbacks for disability organizations having registered charitable status under federal tax legislation and scrutiny? How do domestic and international factors interact and influence the work of disability agencies and activists? What are the implications of the United Nations Convention on the Rights of Persons with Disabilities for state-civil society relations and for the competing disability models of charity, human rights, and medical care?

Democratic politics over knowledge production is not only about advancing reason and shedding informational light on dark areas of unawareness. That politics, certainly in the broad field of disability activism and Disability Studies, is also about multiple forms of knowledge: multiple ways of knowing that interact with, and struggle against each other within particular fields of power relations. Naming these governing techniques, and using critical concepts of power/knowledge that recognize disjunctures in the exercise of authority, can lead to insights into possibilities for mobilization, resistance and progressive reform.

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