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**The Learning Collaborative:
An approach to emancipatory research in disability studies**

Introduction

The debate persists in disability studies about the best ways to learn more about the experience and consequences of disability. Often polarized by inflammatory rhetoric, the discussion is far from rational or impartial (Whalley Hammell, 2006). The classical, epidemiological approach has been virtually dismissed for its association with a medical definition of disability (McDermott & Turk, 2011; Rioux & Bach, 1994). By virtue of locating the origin of the disability in an impairment of mind, body or senses, the epidemiological approach is judged to have nothing to offer to an enhanced understanding of the issues and barriers encountered by people with disabilities (Danieli & Woodhams, 2005). Some commentators even conflate the medical and charitable models of disability, adding a further layer of pity and tragedy to the portrayal of disability (Beauchamp-Pryor, 2011).

Various approaches have held sway in disability studies over the years, including post-positivist, interpretive, critical, affirmative and participatory paradigms (Brown, 2001; Swain & French, 2000). A favoured approach at present appears to be emancipatory research. Featured in the literature for approximately 20 years now, the emancipatory approach is characterized by its focus on political action to confront social oppression and remove disabling barriers (Barnes, 2003; Oliver, 1997). It is grounded in the social model of disability, and as such finds favour in the hegemonic discourse in contemporary disability studies. In a much-quoted article in 1996, Stone and Priestley identified principles that define and govern emancipatory research. These principles require that researchers adopt the social model, surrender any claim to scientific

neutrality, focus on political action for practical benefits to people with disabilities, and render themselves accountable to people with disabilities.

The benefits of the emancipatory approach include its focus on social action and its privileging of the voices of people with disabilities. It seeks not only to generate new knowledge, but to actually remove barriers and promote social inclusion and equality. An important additional benefit that accrues from emancipatory research is the development of knowledge, skills and attitudes among individuals and groups associated with the process, and the inevitable

process (Zarb, 1992; 1997). The research process must be accountable to “insiders”, despite their possible lack of research qualifications or track record in successfully executing research.

How then does one judge who is suitable to be considered an insider – the arbiter of all questions methodological, ideological, theoretical

2009; Prince, 2009). They seek evidence that can assist them in allocating scarce resources to the most compelling problems.

An example: Improving access to primary care

The following is an example of the Learning Collaborative approach in action. The McGuinty government in Ontario came to power in 2006 on a promise of ensuring access to primary care for all Ontarians. It advanced a model of primary health care called the Family Health Team, with trademark characteristics such as 24-7 coverage, interdisciplinary care, rostering of patients to physicians, and chronic disease management (Rosser, Colwill, Kasperski, & Wilson, 2011).

disabilities. We therefore launched a Learning Collaborative to improve access to primary care in Family Health Teams in Ontario for people with mobility impairments.

Step 1: Form the team.

A key focus of the Learning Collaborative is to bring together people with different backgrounds who can learn from one another, and through a convergence of their collective expertise, create meaningful change. Collaborative relationships between academics and disability advocates are not always easy, but in this case, the academic and community partners had worked together many times over approximately 25 years both on research and service projects. We were fortunate to have a team that included researchers with ten-years’ research experience in access to health services for people with disabilities and expertise on the Learning Collaborative approach. Our disability advocacy partner was an organization with primary care as its strategic priority, and excellent relationships with members of the provincial bureaucracy’s primary care team. The team came together regularly to update on the progress of the initiative, to share lessons learned and to plan next steps.

Step 2

is a research and action cycle that takes best advantage of the skills and perspectives of different types of partners – researchers, consumers, policy-makers.

PLAN – The Plan phase involves assembling the best evidence from peer-reviewed literature and other credible sources to address the problem. This phase was spear-headed by the academic research team, but involved all partners, including consumer representatives from the CPAO and policy advisors from the provincial government. This phase utilized a scoping review of the international literature (Arksey & O’Malley, 2005;

While 74% of physicians in south-western Ontario rated their offices as accessible, only 30% of patients found them accessible (Shankardass et al., 2003).

There is consistent evidence that a significant barrier to good quality primary care for people with mobility impairments is lack of accessible examining rooms, equipped with adjustable-height table and lift to assist patients to transfer (Shankardass, Cooper, Walters, Watson, Furlan, Banting, ...Wellington, 2003).

Only 15% of practices in eastern Ontario have adjustable exam tables or ceiling track lifts, to permit patients with mobility disabilities to transfer onto a table and be examined (Author, Shortt, Hunter, Dorland, Godwin, Rosser, & Shaw, 2010).

STUDY – The Study phase was again led by the academic partners. In order to assess the effectiveness of the consumer outreach

The follow-up telephone surveys with the FHT’s showed that the combined consumer organization / academic partnership was compelling in terms of credibility and integrity; Timing was an important determinant of receptivity to the opportunity to increase accessibility. Capital improvements were more readily incorporated once the FHT was operating in a steady state, rather than when they are starting up. Follow-up was required to assist FHT’s with space planning and implementation of accessibility equipment, as they typically had no experience with universal design or accessibility requirements, despite being a part of the health care system.

Family Health Teams made it clear that they still needed training in order to be fully compliant with customer service standard. There may have been an expectation that they should know how to accommodate patients with disabilities, but they really didn’t. In addition, there may have been some embarrassment about not knowing, leading to reluctance to ask questions or seek assistance. There was resistance of the part of some physicians to share the cost of the equipment. There were some expressions of unwillingness by physicians to incur any financial responsibility for accessibility.

ACT – The final phase of the PDSA cycle involves refinement of the outreach strategy and development of tools for broader dissemination. While the initiative originates in local communities, its greatest benefit can be achieved by incorporating lessons learned from the various members of the Collaborative, and expanding the reach of structural change. In this case, our plan is to increase the specificity of the equipment recommendations, explore bulk

purchasing to overcome variations in pricing across suppliers, and enhance the information about the AODA and the legal necessity for compliance.

To date, we have reached out to all 200 Family Health Teams and 25 Nurse Practitioner-led Clinics, to assist them to become accessible to patients or prospective patients with disabilities, and to reach compliance with the AODA Customer Service Standard.

Step 4: Expand the initiative.

The final phase is to expand the reach of the initiative, to effect more broad-scale change. We plan to reach out to other models of primary care delivery and other provinces. A number of collateral initiatives have also arisen. We have been approached by other community disability organizations among our partners to effect a similar change to address the problems experienced in accessing primary care by hearing-impaired individuals, those with speech and communication limitations, individuals with intellectual disabilities.

We have delivered to the Ministry and disseminated among all FHT’s a Primary Care Accessibility Self-Assessment, developed through our prior research. This tool appears among the Ministry’s toolkit for primary care settings, and assists primary care settings to ascertain where they may have barriers to people with disabilities, and where they may ultimately be in

Booth, S., & Kendall, M. (2007). Benefits and challenges of providing transitional rehabilitation services to people with spinal cord injury from regional, rural and remote locations. *Journal of Rehabilitation*, 15, 172-178.

Brown, S. C. (2001). Methodological paradigms that shape disability research. In G. Albrecht, K. Seelman, & M. Bury (Eds.), *Social Disability: A Critical Perspective* (pp. 145-170). Thousand Oaks, CA: Sage.

Carden, F. (2009). *Disability and the Social Contract*. Los Angeles: Sage Publ.

Danieli, A., & Woodhams, C. (2005). Emancipatory research methodology and disability: A critique. *Disability and Society*, 8, 281-296.

Donnelly, C., Author,

Zarb, G. (1997). Researching disabling barriers. In C. Barnes & G. Mercer (Eds.),
(pp.49-66). Leeds, UK: The Disability Press.