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cjdseditor@uwaterloo.ca

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

Mary Ann McColl, PhD, MTS, Queen’s University, Centre for Health Services & Policy
Research
mccollm@queensu.ca

Bill Adair, Executive Director, Canadian Paraplegic Association Ontario
Sue Davey, MHSc, The Osborne Group
Nick Kates, MD, McMaster University

Abstract

The debate persists in disability studies about the best ways to learn more about the experience and consequences of disability. Various research approaches have held sway over the years, but a favoured approach at present appears to be emancipatory research. Due to numerous critiques and caveats, emancipatory research has been referred to as an “impossible dream”. In this paper we offer a way of satisfying the ideological principles of emancipatory research that upholds the highest standards of evidence and policy relevance. It is derived from continuing quality improvement in health care, and is referred to as the Learning Collaborative. We offer an example of the Learning Collaborative approach as it was used in Ontario Canada to improve accessibility in primary care settings. The Learning Collaborative approach is evaluated against criteria for collaboration in disability studies, and found to embrace many of the principles of emancipatory research, specifically: a focus on barrier removal, consumer-researcher collaborations at every stage, and a focus on the priorities of the disability community. In addition, it adds a level of scientific rigour through the use of evidence-based policy analysis and scoping methodology.

Keywords

Collaborative; emancipatory research; disability studies; consumer; community; evidence; methodology

**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 empowerment associated with this development.

Critique of the emancipatory approach focuses on logical inconsistencies and methodological weaknesses. Several researchers note the scarcity of methodological detail or attention to scientific rigour in emancipatory research (Hammersley, 1995; Barnes, 2008; Danieli & Woodhams, 2005). Emancipatory research challenges the dominant research norms, whereby knowledge, expertise and power lie exclusively with academic researchers, and people with disabilities are relegated to roles as research subjects. While critics acknowledge the inappropriateness of this power differential, they entreat disability researchers not to overlook methodology in favour of ideology.

The emancipatory approach has also been criticized for polarizing the research community into "insiders" and "outsiders" (Macbeth, 2010). One is rendered an insider by virtue of having first-hand experience with disability; all others, regardless of their connections, qualifications or commitment to the field, are considered "outsiders". According to the most strident proponents of the emancipatory approach, only insiders are qualified to make decisions in the research

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 or political? Barnes (2008) points out that the singular personal experience of disability offers little assurance that the "insider" has a good grasp of the heterogeneous and often subtle issues that inform disability studies. Being an "insider" to a particular type of disability does not necessarily render one an expert in other areas of disability research (Shakespeare, 1996). Furthermore, the "us and them" approach does little to build successful research teams that can procure funding in a highly competitive arena, and successfully execute and disseminate research. Rather an oppressive dualism divides the research effort, instead of galvanizing it to make meaningful contributions to change (Goodley & Moore, 2000; Macbeth, 2010; Shakespeare, 1996).

A third critique of the emancipatory approach is the need to forgo the illusion of objectivity, and with it any attempt at impartiality or the pursuit of a broader truth. Instead, research is preferred that is candid about its biases, and highly utilitarian in its service to a particular political goal. Emancipatory research is usually characterized by the testimonials of individual voices and narratives. While individual voices have inherent authenticity, they can come across as anecdotal or even sentimental in the eyes of policy makers faced with many compelling priorities (Barnes, 2003).

Transparent self-interest is typically viewed as highly suspect by decision-makers. Policy-makers seek macro-level analysis that persuades not only about the presence of a problem, but also about the scope and magnitude, consequences and implications of the problem (Carden,

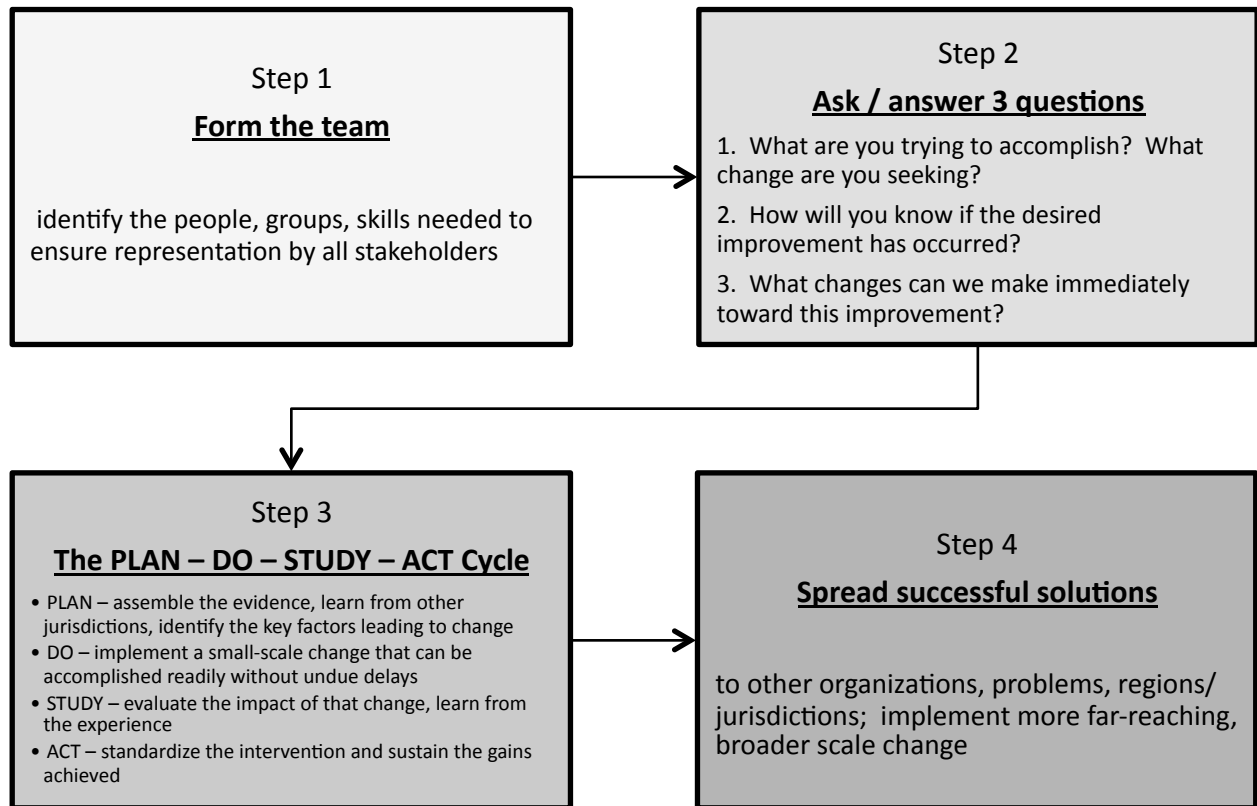
2009; Prince, 2009). They seek evidence that can assist them in allocating scarce resources to the most compelling problems. If research is to make a difference in the structures that disable, then it must be taken seriously by decision-makers, which means that it must uphold standards of evidence applied in other research communities.

All these caveats led Barnes (2008) to conclude that emancipatory research is an “impossible dream”. In this paper we offer a way of satisfying the ideological principles of emancipatory research, while still upholding high standards of evidence and policy relevance. It is derived from continuing quality improvement in health care, and is referred to as the Learning Collaborative (Institute for Healthcare Improvement, 2003).

The Learning Collaborative

The Learning Collaborative is a process aimed at producing accelerated change toward structural improvements. It was originally developed to assist in the re-design of health systems to better incorporate best practices, and to make health care settings more efficient and patient-focussed. Learning Collaboratives are typically localized initiatives, aimed at making immediate and meaningful change, and studying the process of change. Learning Collaboratives consist of high-functioning teams with a commitment to change, strong leadership, open communication, and a variety of skill sets. Learning Collaboratives have been used extensively in the primary care setting, to re-design the office visit to decrease wait times, improve patient flow and enhance physician efficiency (Bodenheimer, Lo & Casalino, 1999). The four-step improvement method typically used by Learning Collaboratives is outlined in Figure 1.

Figure 1. The Learning Collaborative Methodology



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). Despite the concurrent passage of the Accessibility for Ontarians with Disabilities Act (2005), there was no requirement on the part of Family Health Teams to be accessible to people with

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: Identify the goal.

Step 2 involves responding to the three questions featured in Figure 1: What is the overall goal the group is trying to accomplish? How will the team recognize the desired improvements? What changes can be made immediately toward the goal?

The disability advocates, the Canadian Paraplegic Association Ontario [CPAO], identified ensuring accessibility of primary care for its members in Ontario as a strategic priority for the current fiscal year. Furthermore, the published literature is unequivocal that people with

mobility impairments face numerous barriers in attempting to access a reasonable standard of primary care (Author, Forster, Shortt, Hunter, Dorland, Benecki, Godwin & Rosser 2008; Author & Shortt, 2006; Author, Jarzynowska & Shortt, 2010; Author, Aiken, Sakakibara, & Smith, in press). On the basis of these two indicators, we established the goal to make Family Health Teams in Ontario more accessible to people with mobility impairments. The specific change we sought was to have at least one examining room in each FHT’s equipped with an adjustable examining table and/or a ceiling-track lift. This involved two objectives:

- Organizational policy – to have all Family Health Teams identify and prioritize the need for an accessible examining room in their practice, and to request the necessary equipment in their budget cycle;
- Government policy – to obtain funding for the required equipment from the provincial government.

This was a highly focussed initiative with objectives that were achievable, relevant to consumers, timely, important, and consistent with government priorities. The government had made “complex-vulnerable” patients its priority in ensuring access to primary care, and thus were receptive to a focus on disability. In addition, the bureaucracy was aware of the need (under the recently passed Accessibility for Ontarians with Disabilities Act [AODA] (2005) for the primary care sector to be accessible to people with disabilities. As of January 2010, the broader public sector was subject to the Customer Service Standard of the AODA.

Step 3: The PDSA Cycle.

The third step of the Learning Collaborative is the Plan-Do-Study-Act cycle (PDSA). The PDSA cycle is a rapid improvement cycle that focuses on achievable, local structural change. It

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; Levac, Colquhoun & O’Brien, 2010), and emphasized a high standard of methodological rigour. Although clinical trials are rare in this area of research, there was an impressive consensus among studies representing acceptable levels of evidence (Author et al., in press). The evidence assembled made a compelling case that lifts and tables were needed in primary care settings in order for people with mobility-related disabilities to receive an equitable standard of care.

- People with disabilities are high users of primary health care, and yet they experience approximately three times as many unmet needs as their non-disabled contemporaries (Author & Shortt, 2006; Author, Jarzynowska & Shortt, 2010).
- People with disabilities may receive an inferior standard of primary care because they are not properly examined or assessed (Booth & Kendall, 2007; Author et al., 2008; Wullink, Veldhuijzen, van Schrojenstein Lantman-de Valk, Metsemakers, & Dinant, 2009).
- Physicians themselves report that patients with disabilities were considerably more time consuming and complex to treat, and given the many challenges, they often didn’t actually examine them (Author et al., 2008; Wullink et al., 2009).

- 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).
- Primary care settings are unaware of what to do to make their practices and processes more accessible to people with spinal cord injuries (Author et al., 2008; Sullivan, Heng, Camerson, Lunsy, Cheetham, Hennen, ... Swift, 2006).
- Currently, there is no financial assistance to permit family physicians to upgrade their office facilities to make them more accessible. In particular, there is no specific assistance or incentive to acquire this equipment totalling about \$10,000. There are published accessibility standards for family medicine in Canada (Jones & Tamari, 1997), and for Family Health Teams in Ontario (http://www.health.gov.on.ca/transformation/fht/fht_guides.html), but neither are enforced.

All of this information was summarized in a two-page briefing note, and provided to the Executive Director of the Canadian Paraplegic Association Ontario (CPAO) to take the next step.

The plan was to bring this issue to the attention of Family Health Teams and their provincial government funders in Ontario.

DO – The Do phase was led by the disability advocates. The CPAO, through its regional service providers, consumers, and political connections, was ideally positioned to bring the case forward to Family Health Teams and to the provincial government. In consultation with key individuals at the Ontario Ministry of Health and Long-term Care, it became clear that some FHT’s might be in violation of the Customer Service Standard of the AODA, and that the government had a responsibility to assist with compliance. We received assurances from the Ministry that they would receive favourably proposals to enhance accessibility of an examining suite.

The CPAO, with the assistance of a policy consultant, mobilized its members and regional representatives to assist with this issue. They researched and identified high-quality, Canadian-made, cost-effective equipment. Effectively using the voices of consumers from the local areas, they reached out to 19 FHT’s to raise their awareness of the need for accessible examining facilities. These 19 FHT’s were selected to pilot test this outreach initiative because they were recently approved for funding and were in the space-planning phase of their development.

The CPAO offered advice, consultation and information to these 19 Family Health Teams to help them justify specific requests for a particular model and type of adjustable examining table and/or ceiling track lift. All Teams were also provided with the Primary Care Accessibility Checklist – an evidence-based audit of four types of accessibility in primary care: physical barriers, attitudinal barriers, expertise gaps and systemic barriers. The Checklist can be completed by administrative staff in approximately 10 minutes, and is substantiated by previous research (see Author et al., 2010 for details and psychometric information).

STUDY – The Study phase was again led by the academic partners. In order to assess the effectiveness of the consumer outreach initiative, we sought to determine how many of the 19 pilot FHTs actually incorporated the information we provided into their budget requests, and how many of those were approved by government funders. It is important to note that none of these sites had requested accessibility considerations in previous budgets or plans. The pilot survey consisted of both qualitative and quantitative indicators of the success of the outreach initiative. Quantitative indicators included the type and number of equipment requests received by the Ministry. Qualitative indicators included reactions to the information disseminated, intention to improve accessibility, and impact on practice. Qualitative information was collected by follow-up telephone interviews with administrative and medical staff at the pilot sites.

Of the 19 FHTs selected, three were not at the appropriate stage in space planning to be making equipment requests. Two of the remaining 16 did not elect to request the specified equipment, and the remaining 14 made requests and were approved for funding, as shown in Table 1. Six requested the manual barrier-free examination table, 7 requested the power-adjustable exam table, 2 requested alternative table/chairs, and 6 requested ceiling lifts. Seven sites requested both a lift and a table. Seven sites requested more than 1 table, and one site requested more than 1 lift.

A total of 34 equipment requests were made (total budget request \$203,204), of which 23 were approved (approved budget \$84,829). Funding was approved on a cost-sharing basis with the physicians, with the Ministry picking up between 60 and 100% of the cost. Eight sites had two pieces of equipment approved, and the remaining 7 had one each. Many of these practices were multi-site operations. The initiative was intended to establish at least one accessible examining room for each practice.

Table 1. Results of the PDSA Cycle

FHT	Item	# Requested	# Approved
1	No request was made	-	-
2	No request was made	-	-
3	Not at the stage to make request	-	-
4	Not at the stage to make request	-	-
8	Hi-Lo Exam Table - awaiting approved space	1	-
5	Hi-Lo Exam Table – manual adjustment	2	1
12	Hi/Lo Exam Table	5	2
13	Hi-Lo Exam Table	2	1
14	Hi-Lo Exam Table	1	1
15	Hi-Lo Exam Table	1	1
17	Hi-Lo Exam Table	2	2
6	Hi-Lo Exam Table– power adjustment	1	1
7	Hi-Lo Exam Table	1	1
9	Hi-Lo Exam Table	1	1
10	Hi/Lo Exam Table	1	1
11	Hi/Lo Exam Table	3	1
16	Hi-Lo Exam Table	1	1
16	Podiatry Exam Chair	1	1
18	Hi-Lo Exam Table	3	2
19	Bariatric Exam Table	1	1
5	Ceiling Lift	2	1
6	Ceiling Lift	1	-
7	Ceiling Lift	1	1
9	Ceiling Lift	1	1
10	Ceiling Lift	1	1
15	Ceiling Lift	1	1
TOTAL		34	23

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 violation of the Accessibility for Ontarians with Disabilities Act (AODA). The tool considers physical, attitudinal, expertise and systemic barriers (can be obtained from www.disabilitypolicyalliance.ca). We are currently working with the Ministry to develop training materials for FHT's on the full requirements of compliance with the AODA. In these ways, the original modest local initiative has had a number of spin-offs that promise to deliver broader scale change.

Discussion

The paper offers an approach to disability studies that addresses the ideals of emancipatory research: the Learning Collaborative. This approach combines consumer-initiated advocacy for the removal of barriers with rigorous scholarly literature scoping and policy analysis.

Furthermore, it includes empirical evaluation of the impact of the advocacy initiative and knowledge translation to a broader audience of stakeholders. The approach aims to overcome polarization and division in the research enterprise in disability studies, and offer researchers and disability advocates a way to work together toward a common goal. It does so by acknowledging the strengths of each person's / group's contributions, and acknowledging the necessity of partnership and collaboration if the best results are to be achieved.

Whalley Hammell (2006) suggests principles to govern collaborative research approaches in disability studies, drawing on post-colonial and feminist perspectives. Research must be collaborative; inclusive of an action component; based on priorities of the disability community; focussed on the person-environment interaction; sensitive to inter-sectoral issues associated with disability (eg., gender, age, ethnicity); reflexive and critical in its philosophical stance; contributing to a solid evidence base; subject to evaluation by consumers / participants. Each of these criteria apply to the Learning Collaborative method.

By its very definition, the Learning Collaborative approach is undertaken by individuals and groups with a shared identification of a problem. In this case, the collaboration is between disability researchers, disability advocates and policy makers. While each views the problem from a different stance, all are equally focussed and committed to a solution to the problem.

Also by definition, the Learning Collaborative is a means of seeking change and addressing real issues. Researchers, advocates and policy-makers work together toward a particular policy outcome. The researcher’s role is to identify, synthesize and analyze the literature that informs the problem, and where necessary create new knowledge to rigorously and credibly illustrate the scope, magnitude and importance of a problem in disability policy. The disability community’s role is to offer practical experience and advocacy expertise to seek a specific identified change that is well substantiated by the research. The policy partner’s role is to advise about navigating the policy environment and assist in formulating the message so that it can be heard by the stakeholders.

In order to create suitable partnerships in disability studies, it is essential for researchers and disability advocates to find each other – to identify where they have shared interests and agendas. The Canadian Disability Policy Alliance, through its membership and its communications strategy, serves as a focal point for this type of partnership development. Co-led by a community disability organization (the Canadian Paraplegic Association) and an academic researcher, the Alliance places highest importance on real, meaningful, sustainable change in the policy framework that supports (or fails to adequately support) people with disabilities in Canadian communities.

The Learning Collaborative method is about making small, readily achievable changes that can make a difference. It is about modifying the environment to alter the way people operate within it. In our example, it was about changing attitudes at Family Health Teams towards accessibility, changing knowledge of the products available to enhance access and quality of care, changing the physical environment in primary care to improve care, changing budgeting practices to

include considerations that enhance accessibility, and changing government consideration of the scope of its responsibility.

With regard to inter-sectoral considerations, the example cited here considers the intersection of disability and health. It addresses not only the disability issue of accessibility and attitudes toward disability; it also addresses the real need to ensure that secondary complications are attended to in a timely fashion, that age- and gender-specific screening and preventive care are pursued, that acute health concerns can be dealt with efficiently, and that chronic diseases are managed effectively.

The critical-reflexive stance is maintained in the Learning Collaborative approach through the commitment of individuals and groups to sustain the partnership and to honour the contributions of the various stakeholders. Stakeholders in this initiative include disabled consumers, disability advocates, Family Health Team managers and staff, family physicians, provincial government officials and decision-makers, equipment suppliers and manufacturers, disability studies researchers. By learning from each other, we increase the probability of success of the initiative, by taking into account more pertinent and relevant perspectives.

The initiative has contributed not only to the evidence base about primary care for people with disabilities, it has also been highly successful in disseminating that research to constituencies that can use it. This research included secondary analysis of population-based data to discern patterns of utilization of primary care among disabled Canadians (Author & Shortt, 2006; Author, Jarzynowska & Shortt, 2010; Author, Shortt, Gignac & Lam, 2010), longitudinal research on health service utilization and spinal cord injury (Donnelly, Author, Charlifue, Glass, Savic & Smith, 2007), surveys of physician and consumer experiences in primary care of people

with disabilities (Author et al., 2008; Author, Forster, Shortt, Hunter, Dorland, Godwin & Rosser, 2008; Author, Shortt, Hunter, Dorland, Godwin, Rosser& Shaw, 2010; Guilcher, Craven, Author, Lemieux-Charles, Casciaro, Jaglal, 2012). In addition to being published in the peer-reviewed literature, the findings of this research have appeared in consumer-oriented publications, and have resulted in innovative knowledge translation strategies for family physicians, for people with spinal cord injuries, and for government.

The challenge of the Learning Collaborative approach is in the formation of the team that is at the heart of this initiative. It would be naïve to suggest that such a team could be assembled without concerted effort and collaboration by all involved. The success of the team is dependent upon shared research and advocacy interests and expertise, and upon sustained relationships developed over time and characterized by trust. The approach works by transferring leadership back and forth over the course of the initiative, between academic partners and consumer partners, depending upon who has the most relevant expertise for the task at hand. In the example offered here, the key players had a long history of working together in a variety of capacities.

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