

## KEYNOTE ADDRESS: It's Going to Take How Long? Benefits and Boundaries in Community-Based Research

### Abstract

*Some of the most interesting and rewarding research opportunities can involve community service providers, persons receiving their services, university researchers and students all sharing their commitment and curiosity about an issue of shared concern. However, the reality of meeting the needs of all members of these research teams can be complicated by different time and process demands for each group in the partnership. This presentation will explore some of the challenges, frustrations and excitement associated with community engaged enquiry.*

Many years ago, Ira Goldenberg (1971) chronicled his journey between the world of academia and that of inner city youth. In *Build Me a Mountain* he described the birth and growing pains of his mountain, the Residential Youth Centre, where he worked in an innovative community collaboration with a horizontal organizational structure and services provided in a community-based format with an emphasis on the role of non-clinicians. Goldenberg's journey is not unique. His honest and critical reflection on the experience of pushing the boundaries of clinical, organizational and research orthodoxies may be familiar to others who are committed to authentic community-university partnerships where the search for innovation through true collaboration challenges traditional roles and organizational silos. Simply put, community-university partnerships are messy. They demand compromise, often challenge our conceptions about how research should be designed, and pressure us to venture in new directions. They also offer us unparalleled opportunities for new learning and the wonderful opportunity to see the results of our work in action. They give us the chance to make a difference.

We all come to such partnerships in different ways. Goldenberg's mountain resonated for me at a time when I was also working with young people from the inner city. His book introduced me to the possibility that we did not have to work in traditional, reactive ways. Instead, we could create authentic, creative partnerships to develop proactive programs. Years later, I have seen the same mountain building spirit in community and university colleagues and students working on shared interagency collaborations, creative program development and liberatory educational initiatives all in support of persons who have intellectual and developmental disabilities.

Such collaborations form in many ways. Projects such as the 3Rs: Rights, Respect and Responsibility Community-

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University Research Alliance start with small relationships of long standing and grow to include many partner community agencies and university researchers. The 3Rs Project has been developing and evaluating systemic approaches to human rights education for persons with developmental disabilities and their care providers for over a decade. The team has developed a rights educational program for community support staff and managers, and a multifaceted educational program for persons with developmental disabilities. The latter includes strategies for teaching people about human rights enacted in everyday living, and a health knowledge and health rights educational package. Started as a partnership between Community Living Welland Pelham and one Brock University researcher, it grew over the years to include nine Brock researchers with four other researchers from various universities and nine community agencies all supported by a small army of undergraduate, graduate and post graduate students and research assistants (Agnew et al., 2010; Feldman, et al., 2012; Griffiths et al., 2003; Griffiths, Owen, & Watson, 2012; Owen & Griffiths, 2009; Owen et al., 2003; Tardif-Williams, et al., 2007).

Other community-university partnerships may arise to address a pressing direct service need. This was the case with a pilot residential treatment project for youth with dual diagnosis that was created by Pathstone Mental Health and Bethesda services, and supported by graduate students from Brock University's Centre for Applied Disability Studies (Helmecki, et al., 2011). The mountain they faced was creating a residential treatment option for several youth who needed this service that was not otherwise available in Niagara. Pathstone, a children's mental health centre, agreed to provide some residential treatment spaces and Bethesda, a developmental service, provided family support services and dual diagnosis training for mental health staff. Brock University practicum and internship students worked with staff from both agencies in the development and implementation of data collection strategies, behavioural interventions and in a family support group.

Regardless of the initiation, these partnerships share several foundational factors in common. The first is *mutual trust*. Project partners are willing to embrace the expertise of others as

individuals, as members of other professions or groups and to take a leap of faith toward a shared vision of improved quality of life for persons with developmental disabilities. As a Brock student who was involved with the Pathstone-Bethesda pilot project observed, a key foundational factor in that project was collegial "authentic valuing" based on a shared professional history among some of the key partners. If the interpersonal relationships of the key partners are of long standing the leap into a new project may be relatively small. However, for new team members, or for those who do not know one another as people beyond their formal job roles, the leap of trust may be considerable. As with any other interdependent relationships, in community-university partnerships there must be sufficient trust to all allow members to engage in innovation that may involve a certain level of intellectual or practical risk, and to engage in creative problem solving, sometimes in high-pressure service situations. The second factor is a *shared vision* of what the partnership can build together that members could not accomplish alone. A belief in the synergy of shared expertise can fuel partnerships such as the ones briefly described above. The third condition is *patience*. The work of program development and research requires time to articulate shared goals and the strategies to achieve them, to acquire funding, to obtain ethics clearance, to gather and to analyse data to demonstrate the contribution made by the work of the community-university partnership. However, if these conditions are in place, the outcomes of shared work can address issues that individual partners alone may find challenging or even impossible to achieve.

The motivation for community-university partnerships varies but a few environmental conditions are shared by service and educational sectors alike. Goldenberg's work was undertaken in the broader context of the "war on poverty." He believed that "no scientific discipline develops independently of, or unaffected by, the social and political realities of its time" (Goldenberg, 1971, p. 462). Today's context, for those who are committed to services and research related to improving the quality of life of persons with developmental disabilities, includes increasing service needs at a time when financial resources are constrained. There is also an increased focus on the impor-

tance of the use of evidence-based practice. Community-university partnerships can offer a mechanism to address some of these pressures. University researchers, and students looking for practicum and internship experiences, are seeking meaningful opportunities in the community. In return, they bring many skills and ideas to help them undertake projects that community organizations may not have the time or resources to complete alone. In addition, some research funding demands evidence of community partnership opening new doors for shared resources. However, these partnerships are not panaceas and they can bring their own issues.

Some of the challenges that community-university partnerships may face include the willingness of community service agencies to embrace research that, in some cases, may slow the progress of program development. In other cases researchers may have to alter their research methodologies or timelines to accommodate agency needs. Regardless of the direction of the accommodation, partners must be willing to learn from one another; researchers may need coaching about how best to design projects that are minimally intrusive with methodologies that respect agency culture. Agencies may find it helpful to learn about issues related to research protocols.

Challenges for community-university research alliances in addressing issues in the lives of persons with developmental disabilities include the examination of methodologies that benefit participants directly and have a liberatory character as their voices are heard (Mulcahy, 2012). In their very informative review of the complexities of ethics related to research in the field, McDonald and Patka (2012) point out the limitations and the evolution in our understanding of issues such as consent; how do we address the conflict between the right to participate in research and the need to ensure traditional informed consent? In one project with which I have worked, a community team partner reported that one research participant got the impression that we, as researchers, thought she was “stupid” because we asked consent comprehension questions when this person understood the consent on first presentation. Sometimes we inadvertently offend in our zeal to protect the rights of research participants. In the absence of this kind of feedback from the

community agency in the context of a meaningful partnership with insider informants our understanding would not evolve.

Despite the challenges, mountains can be built in community-university partnerships and other kinds of service-research alliances. Perhaps the key is to ensure that partners are willing to align their work by recognizing the added value that can accrue to members of the alliance; by committing to learn together; by recognizing that there is the potential to have immediate impact on an issue of common concern; by capitalizing on the growth potential inherent in creating communities of practice and in being open to new ideas as partners stretch their thinking outside their organizational or disciplinary boundaries. Together we can make a difference, we can build mountains that we could never build alone.

## Key Messages From This Article

**People with disabilities:** You have the right to be part of research projects so you can tell your own story. You have the right to suggest ideas that you think should be researched so we can learn more about how to help people to have better lives.

**Professionals:** Community-university partnerships provide opportunities for exploration of service issues and evaluation of programs that are grounded in authentic practice experience.

**Policymakers:** Community-university partnerships offer opportunities for research that has the potential for immediate and relevant system impact.

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