HEALTHIER TOGETHER:

The CIHR Partnerships Casebook

CIHR IRSC

Canadian Institutes
of Health Research

Instituts de recherche
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Canada

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FOREWORD

Since its inception, the Canadian Institutes of Health Research (CIHR) has adopted a broad and inclusive approach to partnerships. Through relationships forged by our 13 Institutes, a number of Branches and several Initiatives, we have engaged in partnerships with the public sector, private industry, voluntary health organizations and international agencies across the globe.

But why do we partner?

Simply put, we partner because we understand that we are only part of the Canadian health research enterprise. CIHR recognizes that effective health research needs the collective effort of the many people and organizations who are committed to making Canadians healthier. We need to work with our partners to *identify* gaps, *fund* the best research and *translate* new knowledge into better health for Canadians, improved health care and economic growth. Science is also becoming an increasingly interdisciplinary effort. Just as CIHR needs to work with its partners to communicate the impact and benefits of health research, researchers need to consider how they can best reach their counterparts in other disciplines and communicate with audiences beyond the traditional scientific community. Society cannot reap the full benefits of our investments in health research unless the resulting discoveries are applied by other researchers, policy makers, health-care providers, patients, the public, and by the private, voluntary and public health sectors. All of these goals require partnership.

Turning the knowledge uncovered by research into action, or what CIHR calls *knowledge translation*, is a critical aspect of our mandate. We have expanded the understanding of knowledge translation (KT) in health research to include both end-of-grant KT and Integrated KT. End-of-grant KT can include "end-of-project" activities such as publishing papers, giving presentations or even using social marketing to promote the dissemination of findings and encourage their application. Integrated KT involves the people who will ultimately use the knowledge in the research process itself, defining research questions and focussing on solutions. Many of the following partnership case studies describe the incorporation of Integrated KT or end-of-grant KT (or both) in their collaborations.

In this publication, you will learn about some very diverse and influential partnership endeavours. These cover the spectrum of collaboration, ranging from researcher-to-researcher partnerships to university-community-policy maker initiatives. There are two types of cases in this collection: 1) profiles of past CIHR Partnership Award winners, which include the stories of their partnership efforts along with their own words of wisdom; and 2) narratives from the front lines of successful partnerships, which share the history of the collaborations, communication techniques and lessons learned.

A number of important lessons about partnership emerge from these cases:

- **Identify opportunity and take action**
  Dr. Anne Snowdon said it best in the Partnership Profile of the 2006 CIHR Partnership Award Winner (Case #2): "When an opportunity presents itself, even if it's only for a fleeting moment, you have to recognize it immediately and act on it." As Dr. Snowdon's case demonstrates, incredibly successful partnerships can begin by casually discussing projects over a coffee break. Sometimes the unlikeliest of situations can spark creative connections, but only if you pursue the opportunity.

- **Maintain open and frequent communication**
  Communicating effectively and regularly can be essential for building trust and staying focussed on the partnership's objectives. Dr. Brett Finlay highlights the need for regular communication to share expertise and capitalize on overlaps between research teams (Case #8), while Dr. Sandra Jarvis-Selinger emphasizes the need for open communication to maintain links with rural and remote communities (Case #5). Furthermore, Dr. Cy Frank underscores the importance of providing partners with feedback, especially positive feedback, to let people know that they are making progress (Case #10). Effective communication can be a powerful motivator.

- **Recognize that partnership takes time**
  Building trust and credibility in a partnership does not happen overnight. Involving a number of people, perspectives, agendas and schedules in any initiative will take time. Recognizing this potential for delay and addressing it in your overall plans can help the partnership succeed. The Canadian Lung Association, for example, understood that engaging stakeholders at a national level would take a significant amount of time and energy, so they established realistic multi-phased deadlines for developing the National Lung Health Framework (Case #1). They set appropriate timelines for consultation and used creative communication methods to reach as many people as possible without stalling the project for excessive periods of time.

- **Make trust and respect the basis of the relationship**
  It may be common sense to say that a true partnership needs to be based on trust and mutual respect, but saying it and actually putting it into practice are two very different things. In multidisciplinary, multicultural or multi-sector partnerships, it may be easy to slip into a hierarchy of knowledge, expertise or power (depending on the objectives of the project or partnership). Such a hierarchy, however, can become an impediment to cooperation. There can still be one party who assumes more of a leadership role for the collaboration than the others, but that partner must listen to the opinions of its fellow participants and respect their contributions. As the development of the Ktunaxa Community Learning Centres reveals (Case #5), if trust and respect aren't embedded in the foundation of the partnership from the very beginning, external forces beyond the control of the partners could wreak havoc on the relationship.

- **Network, network, network**
  Never underestimate the potential of making contacts. Much like the importance of identifying and pursuing opportunities, networking to promote ideas can lead to remarkably strong alliances. Denis Morrice, for example, describes how making connections with researchers, patients, cabinet ministers and health research funders transformed the arthritis research landscape (Case #4), while Dawn McKenna emphasizes how the networking that comes from workshops and conferences can help create ideas and opportunities (Case #6).

- **Recognize that partnerships can lead to greater impact**
  Recruiting extra expertise, listening to uncommon perspectives and facilitating knowledge translation all help projects achieve greater impact – and all of them require partnerships. The Human Early Learning Partnership, for example, highlights how relationships between researchers, communities and policy makers can lead to province-wide changes in policy (Case #3). The "Feelings in Pregnancy" case reveals how bringing together the right people can lead to the development of a new health service for women (Case #9). Finally, the "Positive Spaces, Healthy Places" partnership shows how engaging community members, researchers and policy makers can lead to better supportive housing for people with HIV/AIDS (Case #14).

CIHR is unique in having a mandate that requires it not only to create new knowledge, but also to translate that new knowledge into health benefits for Canadians and individuals around the world. The partners you will meet in this Partnerships Casebook are passionate, inspirational people who have made a difference in the lives of Canadians across the country. On behalf of CIHR, I thank them for their work.

Dr. Ian Graham
Vice-President, Knowledge Translation
Canadian Institutes of Health Research

ALL IN ONE BREATH:
THE NATIONAL LUNG HEALTH FRAMEWORK

The Canadian Lung Association

Respiratory diseases have a major impact on millions of Canadians. Everything from air pollutants to inhaled drugs can potentially lead to respiratory disease, placing everyone in Canada at some level of risk.[1] In fact, lung disease already affects one in five Canadians and costs the Canadian economy an estimated $154 billion dollars per year in health care costs and lost productivity. The World Health Organization estimates that, by 2020, lung disease will be the third leading cause of death worldwide.[2]

> **The issue:** *Lung disease already affects one in five Canadians. Any attempt to reduce its impact requires the involvement of multiple stakeholders and resources.*

Since respiratory disease encompasses many different illnesses, any attempt to reduce its impact requires the involvement of many agencies, industries and different levels of government. For years, respiratory health stakeholders have been seeking ways to maximize resources, share knowledge and improve services as a way to reduce new cases and manage existing illness.

As the national voice for respiratory health, The Lung Association brought together a broad spectrum of 40 stakeholders in April 2006 to develop a National Framework for Respiratory Health. At that initial meeting, an Interim Steering Committee was established, as were priorities and a general direction for the Framework.

The motivation behind the National Lung Health Framework (Framework) is to address fundamental gaps that exist between the current and desired state of respiratory health in Canada. There are many significant "pockets" of excellence within the overall respiratory health research landscape. The goal of the framework is to develop coordinating mechanisms and protocols that will function at a national level to enable collaboration and the exchange of information, knowledge and resources.[3]

Alignment & Collaboration: The Road to Success

The National Lung Health Framework is a "Made in Canada" initiative, spearheaded by The Lung Association and the Public Health Agency of Canada, and is designed to coordinate efforts for the prevention and management of respiratory disease. The entire approach for the Framework has been a cooperative one, and the development of the plan has been an inclusive process, seeking to maximize opportunities for stakeholder feedback and collaboration.

> **The solution:** *Coordinate stakeholders and strategies through a "Made in Canada" initiative that unites efforts to reduce the impact of lung disease.*

The establishment of the Interim Steering Committee brought together a broad range of perspectives, skills, knowledge and expertise – including those of Dr. Peter Liu, Scientific Director of CIHR's Institute of Circulatory and Respiratory Health (CIHR-ICRH) and Dr. Malcolm King, Scientific Director of CIHR's Institute of Aboriginal Peoples' Health (CIHR-IAPH).

Between April 2006 and April 2007, multi-stakeholder working groups provided input, recommendations and guidance in four specific areas: Chronic Disease, Infectious Disease, Environment and Tobacco Control. These groups were established based on the work being done by the government and stakeholders at the national, provincial, territorial and regional levels, and all four groups presented their findings to 170 stakeholders at the first "Plan for Action" meeting in April 2007. Over the course of two days, participants discussed key strategic priorities, outcomes, objectives and actions to improve the respiratory health of Canadians. They were also introduced to an "Asset Map and Gap Analysis" report, which provided a snapshot of services, research, guidelines and frameworks in respiratory health across the country.

The "Plan for Action" meeting was successful in uniting and informing multiple stakeholders. In fact, over 135 signatures were collected at the meeting for a "Call to Action" that was put forward to politicians and stakeholders throughout the summer of 2007.

Using the information and expertise from these efforts, a draft document was created outlining the core components of the Framework. This document was then presented for review, feedback and input at workshops and meetings held in each province and territory by stakeholders, patients and government representatives. Additional meetings and consultations were held with key stakeholders in First Nations, Inuit and Métis health to ensure the strategies and activities would adequately recognize and address the unique experiences and challenges facing Canada's Aboriginal communities.

> **The approach:** *Input and feedback were gathered from stakeholders by assigning working groups, hosting workshops and meetings, coordinating teleconferences, and giving conference presentations.*

The Interim Steering Committee and its Chair, the Lung Association, listened to requests from the participants of the meeting to expand the membership of the Committee to include an even wider range of skills, knowledge and expertise. In response, the original 19-member Committee conducted an assessment of their own skills and expertise by completing a "Skills and Expertise" questionnaire. Members identified information such as the networks and organizations in which they participated, their topics of research, populations with whom they worked closely, and self-identified skills and expertise that they brought to the committee. An analysis of the results outlined the strengths of the Committee's membership, but it also revealed gaps that needed to be addressed. Relying on both the findings of the assessment and the feedback of stakeholders from the April 2007 meeting, the Committee identified a list of organizations to approach for nominations of individuals to fill the gaps. All of the candidates were excellent, but size and budget restrictions prevented the Committee from accepting them all. In the spirit of collaboration, however, the Committee opened the door for working with all of the nominees through new committees (as they arose) and at provincial and territorial workshops.

Partnership within the Framework

The National Lung Health Framework was created through the efforts of over 500 participants, including individuals, organizations, governments and other volunteer stakeholders. Framework volunteers, encompassing medical experts, non-governmental organizations (NGOs), government, industry, patients, aboriginal groups, environmental groups and many others have contributed the equivalent of well over a million dollars of time to this process. They have conducted background research, participated in the development of cost-benefit packages, designed and reviewed models of care, written documents and communications packages, and spoken to stakeholders in every region across the country.

The result is a comprehensive document outlining the state of respiratory health in Canada, our challenges and a collective solution for addressing them.

The Lung Association and several other NGOs have used the Framework document as the basis for their own strategic plans. Through work as members of the Steering Committee, over 27 organizations and individuals have begun to collaborate to realize all parts of the Framework Action Plan, investing money, time and people to make it a reality. This partnership will be invaluable to realizing the potential of the full Framework and Action Plan, all the while ensuring that, with the participation of federal and provincial governments, it is truly a common strategic plan for the respiratory community.

Moving the Framework to action

Some issues are simply too complex or multi-faceted for a single organization to master alone. The Framework is a network composed of multiple stakeholders who work collaboratively to achieve goals that they could not otherwise accomplish by themselves. The Steering Committee has managed to maintain the strong sense of shared vision and goals that unite the project and, at the same time, has allowed the stakeholders to retain their individual identities.

Within the Framework, each Strategic Area for Action includes both a goal and five to six strategies for achieving success in that area. The stakeholders took the Framework a step further by suggesting strategic *activities* to provide context and direction that would be helpful for meeting goals. By identifying leaders, potential partners, benchmarks and timelines from among the existing projects, programs and initiatives, the stakeholders have helped shape a comprehensive and effective path of action for the initial five years of the Framework. Each strategy will have a set of measurable indicators to determine progress made towards achieving the goal of each Strategic Area

The results: *A common strategic plan for the respiratory community has been developed that enables multiple stakeholders to work collaboratively for the greatest impact. Stakeholders have helped shape a comprehensive and effective path of action for the initial five years of the Framework.*

for Action. A clear set of criteria will also be developed to measure the suitability of each project, program and initiative, ensuring every step of the process is effective and aligned with the Framework's strategies and goals.

Lessons Learned

In order to yield results, The Lung Association ensured that all of the stakeholder meetings and workshops for the development of the Framework were highly structured. The same facilitator was used for all of the meetings, and this proved to be an excellent way of providing consistency and structure, adding context to each discussion and building on previous successes.

In terms of significant barriers, the Framework faced issues of time and money. These contributed to one of The Lung Association's most daunting challenges: engaging a significant number of diversified stakeholders who could affect – and would be affected by – a *national* framework on respiratory health.

The Lung Association overcame these obstacles by using several methods:

• they embraced a policy of transparency and collaboration that allowed them to find partners and allies, maximize resources and connect with stakeholders outside of their traditional group of contacts;
• they were creative in their engagement practices, using a variety of methods (including face-to-face meetings, online/e-mail correspondence and teleconferencing); and
• they attended various conferences and workshops, providing presentations and soliciting questions and feedback from audience members.

Overall, an important lesson learned from the process was to maintain momentum; keeping people very focussed was instrumental in moving forward and maintaining the partnership for the future.

Notes

[1] *National Lung Health Framework Executive Summary*, The Lung Association, Ottawa, Ontario, 2008.
[2] Ibid.
[3] National Lung Health Framework Discussion Document, The Lung Association, Ottawa, Ontario, 2007. Available from **http://www.lung.ca/pdf/research/framework_discussion_document_2007_ES_e.pdf**. Accessed February 2009.

PARTNERSHIP PROFILE:
2006 CIHR PARTNERSHIP AWARD WINNER

Dr. Anne Snowdon, AUTO21 NCE, University of Windsor
Dr. John Mann, DaimlerChrysler Canada (now Chrysler Canada Ltd.)

While working as a nurse in the intensive care unit of a children's hospital in Ottawa, Dr. Anne Snowdon saw too many crippling injuries and young lives lost due to vehicle crashes. Trauma due to road crashes continues to be the leading cause of death, and a major cause of serious injury, in Canadian children under the age of 14. Despite legislation enforcing the mandatory use of vehicle restraints, approximately two children still die or are seriously injured every day in Canada as a result of road crashes.[1] In 2002, Dr. Snowdon, who was convinced that society needed to address this loss of life, embarked on a mission to follow "the simple idea" of saving the lives of children by learning why vehicle crashes can be so devastating for their little bodies.[2]

In his work as Head of Engineering for Chrysler Canada, Dr. John Mann had also all too often been exposed to the tragic results of accidents involving automobiles and young children who were improperly restrained. Industry and government had already been working diligently to understand the causes and mechanics of such injuries and fatalities, and a wide range of effective devices and regulations had been developed to address this important problem. Unfortunately, these efforts were simply not enough; far too many Canadian caregivers were either improperly using child restraints or were ignoring them entirely. It was apparent to Dr. Mann that improved technology alone would never achieve the results that were needed so badly by society.

With support from AUTO21, the federal Network of Centres of Excellence for automotive research, Dr. Snowdon enlisted a multi-disciplinary research team from the University of Windsor and the University of Western Ontario to better understand parents and their decisions about safety seat use.[3] The team surveyed more than 1300 families in southern Ontario and found that parents were generally uninformed about child seat safety and the risk of injury in vehicles, too often giving in to children who didn't want to use their safety seats.[4] Similar studies estimate that while more than 80% of parents attempt to use vehicular safety systems for their children, fewer than 20% do so accurately or effectively enough to truly protect them.[5]

Armed with this information, Dr. Snowdon and her team developed an educational intervention to support safe parental decisions about the use of safety seats. AUTO21 funding and support from Chrysler Canada made it possible for Dr. Snowdon's team to develop a program to teach families how to keep their children safe in vehicles. Dr. Mann assembled a team of industry safety experts to bring knowledge of safety system design, crash avoidance strategies and government regulations to Dr. Snowdon's research group. Together, this extended team developed a multi-media education program for families called *Bobby Shooster Rides Safely in his Booster*. The program has been shown to significantly increase parental knowledge about the correct use of safety seats for children travelling in vehicles.[6]

It was apparent from their first meeting that this could be a true partnership based on mutual interests, complementary knowledge and abilities, and the desire to make a difference. Initially met with curiosity from engineers who wondered how a nurse could be involved in automotive research, Dr. Snowdon quickly recognized the opportunity to explain that nurses study health behavior and that she could provide the discussion with the precise expertise needed to achieve breakthrough results.

Furthermore, both teams understood that no technology, no matter how sophisticated, will work if people choose to ignore it or use it improperly. Dr. Snowdon and her team sought to understand the reasons behind those choices and translate that knowledge into more effective intervention programs. Dr. Mann and his team were keenly interested in the outcomes of that work and how it might translate into better technology and safer transportation for Canadian children. Their goals, despite substantially different methods and backgrounds, converged in a partnership that was mutually stimulating and beneficial.

As a result, Dr. Mann enthusiastically assumed a central role of championing the project within industry and communicating the success of the research team and their outcomes. "Safety affects all of us, no matter what our business or our interests. Who cannot be touched when a child is injured or killed — and particularly when it could have been avoided?" notes Dr. Mann. The commitment of company time, senior executive personnel, and resources underscored Chrysler's steadfast and active support for children's safety. The synergy that developed between the respective teams and their success in reducing injuries and fatalities among Canadian children won them the CIHR Partnership Award in 2006.

> **"**The key is to create partnerships that are meaningful and make real strides…yet, at the same time, offer each partner the opportunity to achieve their individual goals.**"**

Since then, this "simple idea" of saving children's lives has turned out to be a powerful force that has "virtually taken on a life of its own" as it reaches through academic campuses, major international companies, and government agencies, sparking creativity and growth with the involvement of every new group.[7]

"When we talk about the rates of injury and deaths of Canadian children and the potential success of prevention, people listen. The key is to keep them interested enough to want to pursue a partnership," says Dr. Snowdon, who is now an Associate Professor with the Odette School of Business at the University of Windsor and Theme Coordinator for AUTO21's Health, Safety, and Injury Prevention research. "Opportunities for partnership that help save children's lives are always appealing for prospective partners because of that emotional tie. We all either know kids or have kids and everyone wants to help. The key is to create partnerships that are meaningful and make real strides in keeping children safe, yet at the same time offer each partner the opportunity to achieve their individual goals."

Despite the compelling nature of the research, Dr. Snowdon stresses that all the pieces of her team's partnerships didn't just fall into place magically. In reality, she notes, the opportunities for partnership take substantial time and energy to cultivate. "When an opportunity presents itself, even if it's only for a fleeting moment, you have to recognize it immediately and act on it," she

advises. For example, her team's relationship with Magna International, which led to the creation of a new booster seat, started over a coffee break at a research meeting. "When they expressed an interest in my work, I immediately realized the potential for translating my research outcomes into a child seat product with Magna, and right away set a date and time for a meeting with them to discuss it further."

> "You can't expect the partner to live in your world. You need to tell them what you can do together that benefits them directly…and why a partnership is important to achieving success for everyone."

Before the scheduled meeting with Magna, Dr. Snowdon made sure that she did some preparatory work to understand what might interest Magna and what expertise they could bring to the project. "You can't expect the partner to live in your world," she explains. "Researchers are passionate about their work, but we too often think that the world should have the same passion. We can't possibly understand it when we try to sell [our passionate idea] and other people won't buy it. But one of the most important strategies to create partnerships is that you need to give a potential partner the tools to see *how* you can work together. You need to tell them *what* you can do together that benefits them directly, and most important, you need to help them see why a partnership is important to achieving success for everyone." This dialogue is the key to a successful collaboration, notes Dr. Snowdon. "Partnerships are about learning and understanding the perspectives and business objectives of both the research team and the industry partner and then finding the synergies in the partnership that can lead to innovation."

Magna worked with Dr. Snowdon's team to create a booster seat that would protect children *and* fulfil the company's business strategy. "It was clear that our *Bobby Shooster* program had an impact on the parents who received it, but our survey findings told us that we also needed to reach the children who were squirming out of their car seats and complaining about how uncomfortable booster seats are to sit in," explains Dr. Snowdon.

> "Learning the 'language' of partners is an important communication strategy to provide a shared dialogue for discussing, debating and negotiating research goals and objectives."

A new research project was designed to engage children more directly in examining how and why they were influencing the decisions of their parents about the use of child safety seats. "It became clear that we needed to expand our team's expertise from safety seat research with parents and drivers to include the world of children's games and marketing," says Dr. Snowdon. While Magna worked on developing a prototype design for a series of booster seats with the needs and desires of children in mind, partners from George Brown College School of Design worked with the team to design an online gaming strategy to help children understand the importance of using booster seats to stay safe in vehicles. Meanwhile, Dr. Snowdon's team worked with children and their parents in community parent programs to discuss booster seats and what would make them attractive to children. Children designed their "ideal booster seats" and the researchers shared these ideas with Magna to incorporate them into the booster seat designs and the gaming strategy.

The result: injury data from the collision investigation work of Dr. Andrew Howard of the Hospital for Sick Children (another member of AUTO21), the data from Dr. Snowdon's team on parental knowledge, the use of booster seats and the children's own design ideas all converged to support Magna in developing and manufacturing the clek™, an innovative booster seat product that was launched nationally in the fall of 2006.[8]

"I doubt this would have been the first product Magna Aftermarket would have launched had it not been for AUTO21," says Christopher Lumley, Vice-President of Magna Aftermarket, a division of Magna International. "What makes this seat so special is the enthusiastic response from children. Not only are they no longer embarrassed to sit in their seats, they are rather excited about their cleks™."[9]

This unique new product would not have been possible without the strengths and insights of all of the partners involved. "The key to innovation is to bring as many perspectives to the table as possible," emphasizes Dr. Snowdon. "It's the partnership that creates the innovation, not the individual expertise of the researcher or the company."

The diversity of Dr. Snowdon's collaborations has taught her that communication is an essential element in a successful partnership, but she warns that no two partners are the same. She advises people to use specific techniques that work best for each partner, based on the partner's core business agenda and working style. Learning the "language" of partners is an important communication strategy. Engineers in design divisions have a unique "language" they use, while physicians who do collision investigation also have a language of their own. Learning those respective languages provides a shared dialogue for discussing, debating, and negotiating research goals and objectives.

Essential Ingredients for Partnerships

1. *Understand and respect the unique needs and objectives of each partner.*
2. *Identify how each partner can contribute and strengthen both agendas.*
3. *Be open to partnership opportunities, see the potential for a partnership and "run with it".*
4. *Be willing to work together on mutually agreed upon goals and objectives to achieve success. It will not work if the researcher sees the industry partner only as a source of funding.*
5. *Look for partners who offer new and innovative applications of research outcomes.*
6. *Approach the partnership with flexibility in working style to accommodate partner needs and their competing demands.*
7. *Listen carefully to what a potential partner (industry or otherwise) really needs, as opposed to telling them what you think they need.*
8. *Understand and genuinely appreciate each other's timelines.*

Dr. Snowdon also stresses that working with the private sector requires flexibility and patience. "You need to understand that directors and CEOs are extremely busy," she explains. "They have so many things to handle at once that regular meetings are often impossible because they just don't have time. They can't commit to them. [If you try to force them], that could turn into a deal-breaker right away."

When meetings with the private sector do take place, Dr. Snowdon notes they should be short and to the point. "You really need to tell them why they should care within the first 30 seconds. If you go on with a lengthy description of all the details of your research, they will lose interest," she cautions. "Once you have them hooked about why they should care, then you get another 30 seconds to explain how they can get involved and what could be achieved with the partnership. Brevity and clarity are essential for building relationships that partners can trust will be meaningful and productive."

Dr. Snowdon says that, far from being finished, in many ways her work is just beginning. Thanks in part to their relationship with Chrysler Canada, her team has also completed a national child seat survey with Transport Canada and has established a working relationship with them to collect national survey data every two years. The team is also working with George Brown College to develop gaming software to teach children about safety. They are even exploring the realm of artificial intelligence software to "create" artificial societies (based on injury data) with colleagues in computer science. These societies could be used to "test" or examine the impact of interventions or policies such as booster seat legislation or national policy such as Road Safety Vision 2020 (i.e., a Transport Canada policy) on family behaviours. Partnerships with Research in Motion have also resulted in a wireless survey management system that lets researchers analyse survey results in real time. Moving beyond Canada's borders, the research team is also engaging in partnerships with the Global Road Safety Project and the World Health Organization to address road safety in developing countries.

As each partnership develops and spins into additional partnerships, there is a domino effect that underscores the potential for innovation within the process of collaboration. "One partnership opportunity always leads to many more partnerships. Recruit extra expertise, sectors, and centres," Dr. Snowdon advises. "Opportunities are endless."

Notes

[1] Snowdon, Anne. (2008). "The Effectiveness of a Multimedia Intervention on Parents' Knowledge and Use of Vehicle Safety Systems for Children." *Journal of Pediatric Nursing, 23(2)*, 126-139.

[2] Snowdon, Anne. "Saving Young Lives: Meeting the Challenge of Child Safety in Vehicles." Available from **http://www.nce.gc.ca/ awards/snowdonessay_e.htm**. Accessed February 2009.

[3] The AUTO21 NCE is a network of approximately 300 researchers across Canada who work directly with over 240 public and private sector partners in the automotive industry. The AUTO21 network also includes the participation of 44 universities across Canada.

[4] Ibid.

[5] Snowdon, Anne. (2008). "The Effectiveness of a Multimedia Intervention on Parents' Knowledge and Use of Vehicle Safety Systems for Children." *Journal of Pediatric Nursing, 23(2)*, 126-139.

[6] Ibid.

[7] Snowdon, Anne. "Saving Young Lives: Meeting the Challenge of Child Safety in Vehicles." Available from **http://www.nce.gc.ca/ awards/snowdonessay_e.htm**. Accessed February 2009.

[8] Ibid.

[9] "New booster seat 'designed for kids and engineered for parents.'" Available from **http://www.nce.gc.ca/pubs/ncenet-telerce/ dec2006/auto21-dec06_e.htm**. Accessed February 2009.

PARTNERING TO HELP CHILDREN THRIVE:
THE HUMAN EARLY LEARNING PARTNERSHIP (HELP)

ECD Mapping Project Team:

Dr. Clyde Hertzman, Director, HELP
Dr. Lori G. Irwin, Deputy Director, HELP
Joanne Schroeder, Provincial Community Development Manager, HELP
Michele Wiens, Senior Manager, Privacy, Strategic Operations & Knowledge Management, HELP
Dr. Janet Mort, Research Associate, HELP
Jacqueline Smit Alex, former Managing Director, HELP
Jennifer Harvey, GIS Manager, HELP
Gillian Corless, EDI Implementation Manager, HELP
Ruth Hershler, Manager, Data Management
Neda Razaz-Rahmati, EDI Coordinator, HELP

Early childhood is considered to be the most important developmental phase of life. Young children need to spend their time in caring, responsive, language-rich environments, and while parents and other caregivers attempt to provide children with these opportunities, they need the support of their community and all levels of government to do so.[1]

To shed some light on the best ways to develop and maintain this community and government support, the Human Early Learning Partnership (HELP) strives to create, advance and apply knowledge about the biological, psychological and societal factors that influence the health and development of children. Led by Dr. Clyde Hertzman, CIHR-funded researcher and Canada Research Chair in Population Health and Human Development, HELP is an interdisciplinary network of faculty, researchers and graduate students from British Columbia's six major universities.

HELP faculty members and staff have conducted hundreds of presentations across British Columbia to audiences ranging from provincial and federal cabinet and executive committees, to national and provincial non-government organizations (NGOs) and local communities. This active networking has facilitated links between HELP and provincial government organizations (among others) and helped to establish its current relationship with the Early Years Branch of the BC Ministry of Children and Family Development (MCFD). Over the past eight years, this partnership has made a major contribution to enhancing community knowledge about early child development, thereby providing a venue for developing evidence-based policies that help children thrive.

> **The issue:** *The state of early child development varies across British Columbia. This variance represents differences in the qualities of stimulation, support and nurturance experienced by children in different areas.*

The Provincial Early Child Development Mapping Project

The formal partnership began with an agreement between HELP and the MCFD in 2000 to launch the "Early Child Development Mapping Project" in British Columbia. The goal of this project was, and continues to be, the development of a system for monitoring and measuring early child development in communities across the province.

To measure early child development, HELP uses the Early Development Instrument (EDI), which was developed by Canadian researchers Drs. Dan Offord and Magdalena Janus. The instrument, which consists of a checklist that measures qualities ranging from physical health to communication skills, is used to assess the state of a child's development in Kindergarten.

Teachers complete the EDI in February, after they have had several months of interaction with their Kindergarten class, and although the EDI is completed for individual children, the results are not used to label or identify individuals. Instead, the results are grouped (or mapped) geographically by neighbourhood, school district, health area, and provincial levels.[2] To enhance the results, the HELP team also looks at socio-economic elements to better understand how broad social and economic factors influence the development and health of children.

Putting child development on the map

HELP has now implemented the EDI in every school district in the province, making British Columbia the first jurisdiction in the world to have an established, standardized tool for assessing early child development at a population level over time. Measuring the state of development of children across the province allows the HELP team to show variations in EDI results by area (such as neighbourhoods, school districts, or health regions). These variations are taken to represent average differences in the qualities of stimulation, support and nurturance experienced by children in those areas.[3]

> **The solution:** *Engage the provincial government and local communities to recognize the needs and address the gaps in existing patterns of early child development.*

The MCFD proved to be a natural partner for HELP as they translated this knowledge beyond academia. The Ministry had already committed to an infrastructure of community coalitions throughout the province, and they recognized that the EDI presented an opportunity to better inform the coalitions about early childhood development in their local areas. Together, the MCFD and HELP brought the project and its results directly into the communities where children and their families live and learn.

Leveraging partnerships for local impact

The mapped data proved to be a key element in the development of a unique and effective joint government-academic-community initiative. Together with written summaries of the findings, the maps bridged an important gap in the knowledge exchange between community and government

representatives. This common understanding paved the way for effective communication. HELP worked with its government partners to ensure that they understood the importance of supporting communities, while community stakeholders brought their unique knowledge of their children, the contextual understanding of where they live and the desire to see their own children thrive.

Working together with HELP scholars, the MCFD then expanded its funding to support community-based coalitions across the entire province, ensuring that there were local champions in each community. These local champions were given the mandate and ability to use HELP's research data and neighbourhood-by-neighbourhood mapping results to build action plans for families and children in their communities that united multiple sectors (e.g., health, education, police, recreation and the social sector).

> **The approach:** *Research findings and local knowledge were used to build action plans for families and children in each community.*

The majority of the communities use these community maps as key tools for local planning and service delivery, while HELP continues to work with communities and government to use their maps to monitor development and to determine where children are vulnerable (or thriving) across physical, social-emotional and language-cognitive developmental domains.

Lessons Learned

The research team emphasizes that properly supporting local ownership of the issues and their solutions was essential to stimulate change at the community level. For example, the MCFD and HELP understood that working together did not simply mean creating a reporting structure; the partners realized that, among other things, overlap in their infrastructure was important. They jointly hired a well-established community development professional to serve as both the Provincial Advisor to the community coalitions (reporting to the MCFD) and Community Liaison Manager (reporting to HELP) to facilitate the learning and use of research directly within the communities. The Provincial Advisor reported to both HELP and the MCFD through quarterly dialogues, and the coalitions reported to the Advisor semi-annually. This role enabled better use of research in program and policy development and, at the same time, enhanced the capacity of community members to support children in their area. The Provincial Advisor also created venues for sharing data within each community in the province through the reporting of results on both a triennial and "as requested" basis.

Furthermore, HELP engaged the community partners in an effort to ensure that the knowledge that they produce is user-friendly and easily understood. The research team maintains a regular dialogue with its community and government partners, involving them in systematic reviews of its research products. HELP also interprets the research findings in written reports, and members of the research team regularly visit communities for presentations and working sessions designed to assist communities in understanding local results and planning improvements. When research results are accessible, it is more likely that they will be used.

While HELP maintains an open relationship with its government partners, it also meets quarterly with all ministries involved with children to collaborate on the best means of providing all of the children in BC with an equitable start in life. These quarterly meetings are critical to reinforcing the commitment shared by all of the parties and the importance of their work. With common short-term goals and strategically set deadlines, HELP and the provincial government are able to work together with a clear understanding of their joint mission.

The results

British Columbia now has an iterative research and communication network across the province that cuts across sectors and has resulted in mechanisms for continuous feedback and responsive dialogue between academics, practitioners, community planners, educators and government decision makers. This partnership between communities, academia and the provincial government has created a body of knowledgeable stakeholders that is essential for evidence-based decision making. At the policy level, the research results of this partnership have been responsible for informing key provincial decisions about funding allocation related to early child development. Historically, there has been no opportunity in British Columbia to allocate funding based on scientific evidence to this extent or have communities engage to this degree. This partnership has made those things possible, but without the commitment of the governmental partners, effecting change on this scale would have been impossible.

A key ingredient in the success of this partnership was having each party value and respect the knowledge that partners at all levels brought to the collective table. Their strengths combined to raise awareness of the importance of early child development and to improve access to services. Community and government stakeholders alike have now put programs and services in place to reduce the gaps in existing patterns of child development – gaps that the partners can now be certain exist – so that all children in the province have the means to thrive.

> **The results:** *British Columbia now has a research and communication network that cuts across sectors to empower communities. Provincial decisions for funding allocation related to early child development are now based on current scientific evidence.*

Notes

1 Hertzman, Clyde and Lori G. Irwin. (2007). "It Take A Child to Raise A Community: 'Population-based' Measurement of Early Child Development." *HELP Research Brief*, 1. Available from **http://www.earlylearning.ubc.ca/resources_reportspubs.htm**. Accessed February 2009.

2 *Early Development Instrument: What is the Early Development Instrument?*, Human Early Learning Partnership (HELP). Available from **http://www.earlylearning.ubc.ca/EDI**. Accessed February 2009.

3 *Early Development Instrument: A Population Health Perspective*, Human Early Learning Partnership (HELP). Available from **http://www.earlylearning.ubc.ca/EDI/population_health.html**. Accessed February 2009.

PARTNERSHIP PROFILE:
2003 CIHR PARTNERSHIP AWARD WINNER

The Arthritis Society

Nearly 4.5 million Canadians of all ages are affected by arthritis and other rheumatic conditions. A common misconception is that arthritis is exclusively a disease of old age; in reality, population studies indicate that people of working age (20-64) make up close to 60% of Canadians with arthritis.[1] In fact, arthritis encompasses more than 100 different conditions and is the leading cause of deformity and long-term disability in Canada.

Today, arthritis research has made a place for itself in Canada's research community, uniting scientists, clinicians, policy makers, patients and community organizations. As recently as 15 years ago, however, arthritis research was struggling to find its place in the Canadian health research agenda.

As the only not-for-profit organization devoted solely to rheumatic diseases, The Arthritis Society (The Society) has a long history of advocating for more attention and funding for arthritis research and patient services. This made it only natural for The Society to assume the convenor role for "Arthritis 2000", an in-depth consultation with Canada's arthritis community held in 1997.

"For Arthritis 2000, we brought together a packed room of stakeholders," explains Denis Morrice, who was president of The Society at the time and is currently the Canadian Ambassador for the Bone and Joint Decade. "When a diverse group of stakeholders comes together, it doesn't take long for people to realize that so much more can be accomplished by working together and, thus, everybody's agendas also move forward."

This broad-based consultation – the first of its kind involving arthritis – sparked a remarkable response from the arthritis research community, which set its sights on one of the biggest prizes in Canadian science: a Network of Centres of Excellence (NCE) grant. NCEs are federally funded research-and-development hubs that are designed to create new partnerships among the academic, industrial, public and non-profit sectors in order to conduct leading-edge research and knowledge translation activities.[2] Buoyed by the positive energy and momentum generated by Arthritis 2000, a task force led by basic scientists (Tony Cruz, Jeff Dixon and Robin Poole) and clinical researchers (John Esdaile, Cy Frank and Ed Keystone) defined research themes and identified key services needed for a multi-disciplinary, collaborative approach to arthritis research. In 1998, the Canadian Arthritis Network (CAN) received funding from the NCE program and became the first disease-specific NCE.

"Denis Morrice was a real champion for building and strengthening arthritis research," recalls Dr. Jane Aubin, Scientific Director of CIHR's Institute of Musculoskeletal Health & Arthritis (CIHR-IMHA). "Since he sat on a lot of governance committees, he could see that the days of individual or independent researchers working in isolation were at an end. He used every occasion to promote arthritis-research teams. The concept of team-building was integral to the NCE application for CAN and became a defining feature of the Canadian Arthritis Network."

Another key insight that emerged from Arthritis 2000 was that arthritis patients had a great deal to contribute to the research agenda. The Society already had a history of including patients on its governance committees, and this important principle was woven into CAN's committee structure, with a patient advisory committee and patient advocates sitting on the Network's Board of Directors and its various scientific panels. "The ultimate goal of arthritis research," says Mr. Morrice, "is to use new knowledge to meet the needs of patients, and since patients are directly and indirectly affected the most by scientific discovery, they should be part of the research enterprise."

While CAN was a significant milestone, there was still much to be done to put arthritis research on a secure footing. Before the Medical Research Council of Canada (MRC) transitioned into the current CIHR, Mr. Morrice often met with Dr. Henry Friesen, then president of MRC, to discuss the socio-economic impact of arthritis and the need for increased research funding.

"When there was talk of using the United States' National Institutes of Health as a model for CIHR, it seemed like the perfect opportunity for arthritis to get on the map," recalls Mr. Morrice. "We really needed to show why it was time to make arthritis one of the 13 institutes, and finally give it some public and government attention. So we started a campaign where rheumatologists, orthopaedic surgeons and researchers – always accompanied by patient representatives – met in person with every Cabinet minister possible."

The effort paid off. When CIHR was created in 2000, the Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA) came into being. "We knew that arthritis would not get an institute on its own," says Mr. Morrice, "so we brought together the dental and skin groups, since they're considered part of the musculoskeletal system. Dr. Cy Frank was instrumental in bringing this consortium together. The goodwill of the many partner and stakeholder individuals and groups who agreed to align was also key."

> **"** *You don't need an army [to be heard]; you need thoughtful, passionate, and committed spokespeople.* **"**

To date, CIHR-IMHA has invested millions of dollars in arthritis research and continues to do so.

Since the creation of CIHR-IMHA, The Society has worked closely with the Institute to develop the network of everyone involved in research on arthritis, from funders to researchers to patients. Together with other partners, The Society and CIHR-IMHA were instrumental in releasing "Arthritis in Canada", the first-ever publication to paint a comprehensive picture of the impact of arthritis in Canada.[3] Bringing together data from national population health surveys, mortality data, provincial physician billing, drug databases and data on hospital admissions and day surgery procedures, the report underscored the need to understand the tremendous burden that arthritis placed on individuals and society as a whole.

Within a decade, one million more Canadians are expected to have arthritis or a related condition and they, like the millions of Canadians already affected by arthritis, have been given a voice with the help of The Society. The Society supported the creation of the Canadian Arthritis Patient Alliance (CAPA). It also championed the Canadian Arthritis Bill of Rights (2001) for arthritis patients, which has resulted in the inclusion of patients as full partners in the research process.[4]

"We really recruited terrific patients to speak about the need for more arthritis research and for an Arthritis Institute," says Mr. Morrice. "You don't need an army [to be heard]; you need thoughtful, passionate, and committed spokespeople. We were always feeding important information to CAPA, even before it was an official organization. Two people in particular, Ann Qualman [founder of CAPA] and Jim Davies, were instrumental. When Dr. Tony Cruz set out to get an Arthritis Network from the Networks of Centres of Excellence, it was Ann who attended countless meetings with government officials and Cabinet Ministers.[5] When we were striving to get an arthritis Institute within the soon-to-be CIHR, Jim would set up the meetings with politicians and Ann would drop whatever she was doing to make the case for an Arthritis Institute."

Both Ann and Jim passed away in 2007, and Mr. Morrice still remembers the remarkable number of people who travelled across the country for their funerals. "A lot of the members of CAPA have become life-long friends. That's the power of networks."

> ❝*Those affected by a decision should be involved in making the decision.*❞

In fact, Ann's legacy still resonates throughout the arthritis research community today: "Those affected by a decision should be involved in making the decision." The Society includes patients on their committees, and most arthritis researchers enthusiastically include the input or collaboration of patients in their grant applications.

In an effort to further enhance the networks within the arthritis research community and to respond to the impending surge of arthritis cases, The Society, CAN and CIHR-IMHA jointly hosted the first Osteoarthritis Consensus Conference in Canada. Held in April 2002, this conference brought together Canadian and international experts and researchers, arthritis patients, policy makers, industry and other stakeholders. The conference was a high-level brainstorming session where everyone, from researchers and medical experts to trainees, disease advocates and patients, was allowed their say in determining the future direction of osteoarthritis research in Canada.[7]

"We were really striving to create synergy with other stakeholders," recalls Mr. Morrice. "Everyone could see a role for themselves, and no one could feel more important than others."

The success of the Osteoarthritis Conference prompted The Society, CAN and CIHR-IMHA to join forces and create the Alliance for the Canadian Arthritis Program (ACAP). Dr. Cy Frank, then Scientific Director of CIHR-IMHA, played a leading role in the development of ACAP, while The Society provided the administrative support. Established in 2003, ACAP is now a coalition of over 20 stakeholder groups dedicated to fighting the burden of arthritis, encouraging government to dedicate resources to arthritis research and care, and supporting those living with the disease. ACAP provides a venue for arthritis stakeholders to collaborate and strategize on arthritis issues.

"We have distinct individual roles and partnership roles to play in the overall arthritis research landscape," explains Dr. Aubin. "The biggest bang is not just from agreeing to partner, but is also from recognizing your distinct roles. Working in the same area can lead to some competitiveness between the parties involved," she admits. "Put that on the table right away. Joint roles and individual niches can then be defined for the mutual benefit of the partners and other stakeholders, including the patients."

"You can't always align your priorities, and that has to be OK," says Mr. Steven McNair, the current President and CEO of The Society. "You're not at a meeting to sell a point of view; you're there to hear them. It's about understanding the other perspectives. The important thing is to keep your eye on the ultimate goal and for each of us to do our best to make it a reality."

> ❝*The important thing is to keep your eye on the ultimate goal and for each of us to do our best to make it a reality.*❞

With more than 60 years' experience, The Society is a role model for achieving results based on relationships of mutual trust, respect, and commitment. "When you approach potential partners, whether they're from the private sector, the voluntary sector, or consumers, it's important to demonstrate passion for the cause," reflects Mr. McNair, who joined The Society from the corporate world in 2008. "Offer value in their terms or language, and remember that it's not just about having a business focus – it's about the needs of people with arthritis and blending our passion with professionalism."

When it comes to building partnerships from the ground up or across sectors, Mr. Morrice advises people to place themselves strategically. "It's all about relationship-building and networking," he advises. "When The Society organized meetings, we made sure that we always had co-chairs. We would have, for example, a rheumatologist from Manitoba co-chairing with a physiotherapist from Prince Edward Island. They would start talking about their work, their region, their patients. Suddenly, a connection would be made. First, get people on board – then make connections between them. You can't build something without a network of support. It's about seeing opportunity and grabbing it."

Notes

[1] *Arthritis Research – The Largest Subset of All Musculoskeletal Disorders*, CIHR, Ottawa, Ontario. Available from **http://www.cihr-irsc.gc.ca/e/11196.html**. Accessed February 2009.

[2] Networks of Centres of Excellence Home Page. **http://www.nce.gc.ca/index.htm**. Accessed February 2009.

[3] *Arthritis in Canada: An Ongoing Challenge*. Available from **http://phac-aspc.gc.ca/publicat/ac/index-eng.php**. Accessed February 2009.

[4] *The Canadian Arthritis Bill of Rights*, The Arthritis Society, Toronto, Ontario, 2001. Available from **http://www.arthritis.ca/local/files/advocacy/Bill%20of%20Rights.pdf**. Accessed February 2009.

[5] Morrice, Denis (2007). "Ann Qualman: Making an ever lasting difference". *CAPA Voices*, Fall 2007. Available from **http://www.arthritispatient.ca/index.php/resources/ann-qualman-making-an-ever-lasting-difference**. Accessed February 2009.

[6] Ibid.

[7] *Summary of Osteoarthritis Consensus Conference 2002*. Available from **http://www.arthritis.ca/look%20at%20research/ oaconference/default.asp?s=1**. Accessed February 2009.

PARTNERING TO EMPOWER COMMUNITIES: THE (ONGOING) STORY OF KTUNAXA COMMUNITY LEARNING CENTRES

Sandra Jarvis-Selinger, PhD
Faculty of Medicine
University of British Columbia

Helen Novak Lauscher, PhD
Faculty of Medicine
University of British Columbia

Kendall Ho, MD FRCPC
Faculty of Medicine
University of British Columbia

Don Maki
Traditional Knowledge and Language Sector,
Ktunaxa Nation Council

Velma Hogan
Aboriginal Liaison, East Kootenays,
Interior Health Authority

Like many geographically isolated locations, rural and remote First Nations communities in Canada often have limited access to health professionals. This situation can have a negative impact on the health of a community, and improving it can be complex: it not only requires better access to health professionals, but it also requires outlets for providing accurate health information whenever community members need it.

To proactively address these issues, a community-university partnership developed and flourished between the eHealth Strategy Office in the University of British Columbia's Faculty of Medicine (UBC) and the Ktunaxa Nation (pronounced "tu-na-ha"). Together, these partners have allocated CIHR funding to develop, implement and evaluate four pilot Ktunaxa Community Learning Centres (KCLCs) in the Ktunaxa Nation communities of Akisqnuk, Aqam, Lower Kootenay, and Tobacco Plains.

> **The issue:** *Rural and remote First Nations communities in Canada often have limited access to health professionals and accurate health information.*

The KCLC Concept

A learning centre is made up of two interconnected components: 1) a community-based facility equipped with Internet-linked computers that are freely accessible to all community members; and 2) online resources that are relevant to community-defined health priorities and developed by community members.[1]

The intent of the KCLC model is to create a space where community members can access trusted health information and socialize in a community setting. KCLCs are first and foremost developed "by and for" their respective communities. This means that UBC provides technological and research mentorship (where needed) in the initial development of the KCLC, but the ultimate goal is the construction of learning centres that are sustained by the community for its own uses, even after the grant funds end.

In fact, as an ongoing resource, KCLCs are designed to incorporate information on social health factors such as traditional medicine, language, and knowledge. This traditional knowledge has provided a concrete opportunity to use and revitalize the Ktunaxa language.

One partnership leads to another

The partnership began in 2003 when UBC researchers completed a "telehealth readiness assessment" with nine First Nations communities across British Columbia, including the Ktunaxa Nation. A telehealth readiness assessment, generally speaking, involves investigating a community's capacity to use information and communication technology to deliver health services and information over a distance.[2] The relationship for this project began when UBC researchers attended a First Nations Technology Council conference in Prince George, BC. The conference organizers were very helpful and referred the UBC team to 20 First Nations communities who were potentially interested in participating in the telehealth readiness assessment. The UBC team heard back from nine communities and engaged them all.

After the results of the telehealth assessment were sent to all of the communities, UBC and the Ktunaxa Nation continued to brainstorm about ways in which they could continue to work together. Meanwhile, the UBC team members were also engaged in partnerships with German researchers who were developing principles for performing "needs assessments" for information technology users, and a health science team in Mexico that was developing the community learning centre model. In addition, Industry Canada launched its Broadband Rural & Northern Development Fund initiative "to deploy broadband internet to un-served communities".[3]

> **The solution:** *Engage the community to develop learning centres and online resources that meet individual community needs.*

These seemingly unrelated events actually paved the way for UBC and Ktunaxa to continue building their partnership:

- the UBC team members were able to hire a researcher to apply the German principles for needs assessment to guide the engagement process for developing the KCLC infrastructure;
- the presence of KCLCs in the community proved that broadband was needed in the area, providing the application to Industry Canada with specific examples of how the infrastructure could be used;
- the willingness of the Ktunaxa communities to pilot the learning centres provided the UBC-Ktunaxa team with the perfect opportunity to apply the Mexican model of community learning centres in Canada; and
- the CIHR project funding supported the hiring and training of community-based evaluation and technology leads in each community to develop, implement, update, and evaluate each KCLC.

Both the university and the community saw the need – and opportunity – to work together in a partnership that had the potential to substantially benefit both parties.

Engaging the community – from the very beginning

The principles of "Ownership, Control, Access, and Possession (OCAP)" were central to the community engagement process throughout the KCLC project .[4] Engagement began immediately, with verbal approval and support from the Ktunaxa Nation Chief and Council prior to the start of the project. Letters of common understanding were also co-written and signed by each of the band administrators and by UBC.

The KCLCs continue to be directed and evaluated by community members, thus ensuring respect for the traditions of knowledge in each community, the inclusion of information that is relevant to specific community contexts and the provision of employment opportunities for community members. Each KCLC has a community evaluation lead and a technology lead who work out of the centre. The evaluation lead manages the KCLC, helps to identify community-based health content for the web-based resources and evaluates KCLC usage over time. The community technology lead, besides maintaining the equipment, creates and updates the web-based resources. All of the community personnel have also contributed immensely to the vision and direction of the KCLCs.

True engagement also requires open communication, and the KCLC team recognized that the success of any project involving multiple partners working from a distance, and from different cultures, would depend on a structured, cooperative communication strategy. In this project, the strategy began with the university team travelling to each community for town hall meetings. Once community personnel were hired for each KCLC, teams met regularly by phone and e-mail, and intermittently at face-to-face meetings. Community and research team members communicated regularly to deal with administrative tasks, collaborate on education and training events, problem-solve or simply share information. They also collaborated to guide the direction of implementation, evaluation and sustainability of the centres.

> **The approach:** *Verbal approval and support was sought from the Ktunaxa Nation Chief and Council, and the underlying principle of building the learning centres was that they would be designed "by and for" the individual communities.*

This regular contact between the partners helped to maintain the focus on the project's goals. E-mail was originally the primary tool used to keep everyone informed about timelines, tasks and budget, while the phone was used to follow up on specific issues that needed to be solved through immediate consultation. Recent support from the BC Rural and Remote Health Research Network (BCRRHRN), however, has allowed the KCLC team to hold weekly meetings via WebEx.[5] WebEx not only has visual and audio connections, but it has also served as a tool for the KCLC team to collaboratively assess the relevance of health information resources, develop and edit appropriate health information and plan conference presentations. Finally, face-to-face communication was strategically used for team development and for the public launches of the KCLCs.

The identification of a single communication lead who was able to maintain a level of continuity throughout the project was also vital to the success of the team's communication. Without this management and moderation, the communication plan would not have been successful.

Lessons learned

The KCLC team originally underestimated the time that it would take to plan and establish the first community learning centre. Their funding was scheduled to last for three years, so the initial goal was to get the first KCLC in place within six months. The entire process, however, actually took about one year. The UBC team realized that this delay was due, in large part, to the fact that while they had developed a small management team with key *political* people from the communities, including sector boards and directors, the plans had not initially filtered into the rest of the community. The momentum of the planning process needed to be felt at the community level, ensuring that community members learned of the initiative after the CIHR funding was secured and the hiring process had begun.

The KCLC team also learned an important lesson about role designations. When the team first applied for their CIHR grant in 2005, one of their community partners was listed on the application as a Principal Investigator. At the time of the grant, however, community partners were ineligible for that role on a CIHR application – a limitation that was revealed only during the CIHR review process. The immediate solution was to remove the name of the partner from the Principal Investigator list in order to quality for CIHR review. While CIHR has since changed its eligibility restrictions in its applicant categories, if the UBC team hadn't already gained the trust of their community partners through the telehealth project, the entire partnership might have dissolved. This experience underscores the fact that forces *outside* of the immediate partnership can significantly influence perceptions *within* the partnership. Open communication, mutual trust and respect must be embedded within the foundation of the relationship in order to negotiate these obstacles when they occur.

The future of KCLCs

The Ktunaxa evaluation leads worked with the UBC research team to complete the overall evaluation of each KCLC. Preliminary evaluation findings indicate great enthusiasm for having a KCLC as a resource in each community.

To date, children and youth have shared their technology skills with adults and elders, who have in turn helped the youth to contextualise the information that they have discovered online. Non-professional health providers in the community have been able to access educational resources that will help them deliver better health care. Community leads continue to be employed to build learning centre resources, and their work provides them with the opportunity to collaborate with community educators in learning traditional knowledge, such as language and local medicines.

> **The results:** *The learning centres became valuable resources for each community. The KCLC model will be used to construct tailored learning centres with 14 First Nations communities in the Yukon.*
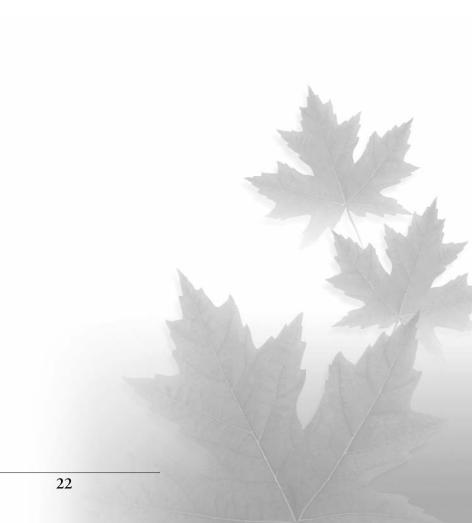
This respectful partnership has been such a success that the KCLC team is currently hoping to use this model to create learning centres within 14 First Nations communities in the Yukon. Funding has been secured through the Michael Smith Foundation for Health Research (MSFHR) to allow the UBC-Ktuanxa team to travel to the Yukon for a knowledge sharing workshop. Community

members from the Ktunaxa Nation and UBC team members will assist in the development of these new Yukon centres. The KCLC team hopes each member will tell the stories of the centres from their own perspective, discussing the unanticipated successes and challenges of the process and teaching others about how the centres were set up to be self-reliant.

The KCLC team notes that, while the individual partners had the skills to promote the development of the project, their collaboration and cooperation created a synergy that will hopefully translate to other communities in the future.

Notes

[1] Jarvis-Selinger S, Novak Lauscher H, Bell B, Ho K. "Tl'azt'en Learning Circle: Information Technology, Health and Cultural Preservation." *Journal of Community Informatics.* Manuscript Accepted with Revisions.

[2] Ho, Kendall, Sandra Jarvis-Selinger, et al. *The Role of Telehealth in Improving Access to Health Services and Education in British Columbia's Rural and Remote First Nations Communities.* Division of Continuing Education, University of British Columbia. 2004.

[3] *Audit of the Broadband Rural and Northern Development Pilot Program*, Industry Canada, 2007. Available from **http://www.ic.gc. ca/eic/site/ae-ve.nsf/eng/00352.html**. Accessed February 2009.

[4] *OCAP: Ownership, Control, Access and Possession*, National Aboriginal Health Organization, Ottawa, Ontario, 2007. Available from **http://www.naho.ca/firstnations/english/documents/FNC-OCAP_001.pdf**. Accessed February 2009.

[5] Webex Homepage. **http://www.webex.com**. Accessed February 2009.

PARTNERSHIP PROFILE:
2008 CIHR PARTNERSHIP AWARD WINNER

Dawn McKenna
Executive Director, Down Syndrome Research Foundation

The Down Syndrome Research Foundation (DSRF), located in Burnaby, British Columbia, is thriving. The independence of the Foundation and its close working affiliations with universities and medical facilities create unique opportunities for cross-disciplinary and innovative research collaborations. These collaborations, however, haven't just happened overnight. They have grown over time, thanks to the diligence and passion of the staff at DSRF. Starting small, but ensuring high quality in all of the organization's activities, DSRF has evolved into a powerhouse of world-class research, a reliable service provider and a credible source of current, practical and usable information.

Established in 1995, DSRF is the creation of the late Josephine (Jo) Mills, the organization's founder and inaugural Executive Director. Over thirty years ago, Jo worked as a physiotherapist and part of her caseload included people with cerebral palsy and Down syndrome. "She felt it was much more difficult to get equipment and services for people with Down syndrome," explains Dawn McKenna, the current Executive Director of the Foundation. "Always the advocate for the underdog, she pushed for proper care, especially doctor's appointments, for people with Down syndrome."

Since the founding of DSRF, the organization's staff has expanded to include speech and language pathologists, educators, medical professionals, researchers, financial management personnel and a librarian.[1] Jo started the organization with the dream of bringing together researchers, clinicians, educators and the families of children with Down syndrome, so the Board of Directors was strategically built from the very beginning to enable linkages between these groups. Members of the Board include business professionals, academics, researchers, educators and family members of people with Down syndrome (with some overlap between the categories).

"The idea was to get a lot of different kinds of expertise involved in the organization," notes Dawn, who left the corporate world herself to become the organization's Director of Finance in 1999. "The set-up works very well. The Board works as an excellent mechanism for governance and guidance. They help us define the scope of our goals, but we keep the freedom to achieve those goals through in-house decisions. The Board members are kept apprised of our decisions, of course, and most of them are engaged with our other committees, as well."

In addition to getting a variety of perspectives and expertise *into* the organization, Jo was interested in putting together information and getting it *out*.

"Communication goals have always been there," says Dawn. "The whole idea is to disseminate information and get programs out there. DSRF's aim is to take effective programs – which we know are effective because we constantly test them – and get them out across the country [for use in different regions]."

To "get programs out" across the country, DSRF has relied heavily on workshops and conferences. "It's the networking that helps create ideas and opportunities," Dawn explains. Not only did she step in as Chair of the 9th World Down Syndrome Congress in Vancouver in 2006, but Dawn has also helped organize numerous conferences and workshops, including a gathering of 25 researchers from 18 different universities to explore potential collaborations. "The excitement and ideas that come from an event like that are incredible and provide an opportunity for experts from diverse disciplines to share and develop new research initiatives."

Back when DSRF first began, it was the excitement and potential for collaboration that led Jo to make some important connections. She liaised with a lot of paediatricians and professionals in the field. This networking led to a relationship with a key partner in the growth of the Foundation: Simon Fraser University (SFU).

"The affiliation with SFU wasn't planned consciously," recalls Dawn. "Jo got involved with some researchers through some workshops and meetings she attended, and our current relationship with SFU grew out of a collaboration with just a couple of people at the university."

> **"** *The excitement and ideas that come from conferences and workshops are incredible and provide an opportunity for experts from diverse disciplines to share and develop new research initiatives.* **"**

This affiliation with SFU has deepened over the years, and the university became instrumental in securing funds for state-of-the-art brain imaging equipment for the Foundation. When Dawn joined DSRF in 1999, it was still based in a trailer on the grounds of Vancouver's Sunnyhill Health Centre. After a successful capital campaign that raised $3 million to construct a specially designed 12,000 square foot Centre for DSRF, the Foundation teamed up with researchers at SFU to raise funds to purchase a brain imaging device known as a Magnetoencephalography system (MEG). The MEG is a completely non-invasive and unthreatening way to measure functional activity in the brain. The total cost of installing this laboratory in the basement of the DSRF Centre was another $3.2 million, which was covered by private benefactors of the DSRF ($0.8M), SFU ($0.6M), the British Columbia Knowledge and Development Fund ($1.4M), and the Western Economic Diversification Fund ($0.4M).

Dawn is quick to point out that DSRF couldn't have established the laboratory without the help of the university. Not only did SFU contribute to both operating and capital expenses, but they also shared their expertise in applying to provincial and federal sources. "SFU had the knowledge and resources to write the [applications for] government grants," she explains. "These grants also have to be held by a university [as a host institution], so without SFU, DSRF wouldn't have been eligible for funding at all."

Research groups at SFU are now the primary users of MEG, and SFU remains the host institution and transfer payment agency for operating grants supporting the MEG Laboratory, but the relationship has expanded beyond sharing resources. Principal Investigators of DSRF, who hold positions at SFU and other universities and hospitals throughout Canada and the United States, are scientists who make continuing commitments to DSRF. They make these commitments through their research and training activities, but they also support DSRF's research infrastructure through membership in standing committees and grants programs.[2]

Not only is research being done at DSRF, but results are also being carefully disseminated through the Foundation. DSRF produces and distributes its own quarterly newsletter and co-publishes a journal for the professional community with Down Syndrome International. The Foundation is also the home of a library with over 1600 books, journal articles, videos and DVDs on Down syndrome that are available for loan to all registered members of DSRF in Canada. DSRF also hosts a Parent Appreciation Day each year. This day is designed to share current research findings with families and other caregivers, and it provides an important arena for researchers to interact with families, to present new scientific results in non-technical terms and to consider applications and strategies for intervention.[3]

Astonishingly enough, even with all of these activities, DSRF does not have any dedicated communication or knowledge translation staff at the organization. Dawn credits her staff and Board of Directors with the passion and creativity needed to distribute information to the appropriate places. "Our 'information guru' is our librarian, who has a Masters in Library Sciences," explains Dawn. "Otherwise, our strategies for knowledge translation or communication are generally discussed in-house on a case-by-case basis." Research results and the Foundation's pilot programs are disseminated to the community through workshops, websharing, conferences with networked organizations, government affiliations, as well as through standard academic and community service channels.

Even the DSRF Centre itself is designed to promote collaboration and knowledge translation. The building was designed to support the meaningful interaction of families, researchers, educators and clinicians. Its layout includes a lounge and reception area, the Foundation's library, indoor and outdoor play areas, medical clinics, offices, classrooms, rooms for assessment and training and research laboratories. The Foundation's aim is to create a dynamic environment where researchers and clinicians work together with affected individuals and their families to apply the knowledge they gain

> *"Know what you want to accomplish before you seek out a new partner and try to get them excited about what you do."*

through research.[4] Providing researchers day-to-day access to families in a supportive and friendly environment has enabled a culture of mutual respect, and has enhanced communication and collaboration. The Foundation also employs and trains individuals with Down syndrome, allowing researchers to see first hand the unique challenges that these individuals encounter on a daily basis and the varying abilities that they possess. This insight into real life has influenced both attitudes and research paradigms.

While she stresses the need for building any relationship on trust and open communication, Dawn's advice to others who may wish to establish a working relationship with a university or research team is to start with a conversation. "Know what you want to accomplish before you seek them out, and try to get them excited about what you do."

The dedication of the Foundation illustrates how well-executed research partnerships can transform big ideas into reality, and the example that it has set won the organization the CIHR Partnership Award in 2008. The research made possible by DSRF and its commitment to translating these research results into an improved quality of life make the Foundation an outstanding model of research partnership and collaboration.

Notes

[1] *Challenging Disability 2006-2008: Down Syndrome Research Foundation Research Report*, Down Syndrome Research Foundation, Burnaby, British Columbia, 2008. Available from **http://dsrf.org/view/inform/articles/14933.pdf**. Accessed February 2009.
[2] Ibid.
[3] Ibid
[4] Ibid.

The Youth Pathways Project:
Getting Creative to Reach Toronto Street Youth

Patricia G. Erickson, Ph.D.
Senior Scientist, Centre for Addiction
& Mental Health
Professor of Sociology and Criminology
University of Toronto

Lori E. Ross, Ph.D.
Research Scientist
Social Equity & Health Research Section
Centre for Addiction & Mental Health

Katharine King, M.A.
PhD candidate
Department of Sociology
York University

Christine Wekerle, Ph.D.
Associate Professor
Faculty of Education
The University of Western Ontario

We know very little about effective interventions for the extremely vulnerable population of adolescents who live in high-risk environments on or close to the street. Studies of homeless youth generally find that poly-drug use, mental and physical health problems frequently co-occur in members of the population. High rates of substance abuse, however, can be seen as coping mechanisms and many of these youths have histories in violent or sexually abusive family homes. This, in turn, may lead them to expect to be victimized or to experience challenges with interpersonal closeness and trust in relationships.[1]

The issue: *Adolescents living on or close to the street represent a vulnerable population that is often hard to reach. Little is known about effective interventions that could influence their pathways into a more stable, healthy adulthood.*

To address these complex issues, the Youth Pathways Project (YPP) brought together a multidisciplinary research team and front-line partners serving homeless youth. Focussing on street-involved adolescents in Toronto, Ontario, the project has generated new knowledge about the characteristics of homeless youth and the factors that influence their pathways into a more stable and healthy adulthood or, conversely, a continued existence on the street.[2]

The study also involved qualitative work on youth experiences of street involvement, and this provided an outlet for the voices of the youths themselves.[3] The team interviewed 150 adolescents to learn more about the quality of life they were experiencing on the street, and they were struck by the articulate and candid nature of the stories. The youths proved to be very insightful, both when speaking about the numerous issues captured by the research team in their data, and in how their stories portrayed the nuances of the research findings. This discovery pointed the way to an innovative strategy for sharing the research findings and the stories themselves.

From words to web

The YPP was built on a combination of research funding from CIHR and the Social Sciences and Humanities Research Council (SSHRC). When the interviews of the initial YPP were completed, the research team successfully applied for further funding from SSHRC to disseminate the youths' stories through the creation of a website. This website, now fully up and running (**www.tyss.org**), is a web-based story-telling project that, in part, presents the results from the YPP study in the words of street-involved and homeless youth.

Designed to raise awareness of the problems faced by homeless youth, reduce the stigma and discrimination they face in their daily lives and empower youth to identify health and other resources that are available to them, the website is unique in that it is both personalized and evidence-based. The results of the YPP study are presented in three reader-friendly reports, written to be accessible to youth, service providers and the general public. The main portion of the website is devoted to stories, poems, drawings and quotations contributed by the youths themselves, and the format of these submissions enables street-involved youth to communicate their experiences to policy makers, educators, the public, service providers and other youth who are potentially at risk.

Building momentum through partnerships

The entire project, including the study and the website, has been collaborative. Researchers and project staff brought together backgrounds in psychology, psychiatry, sociology, social work and education to develop and implement the YPP. The formation of the partnership between the researchers and the community agencies was facilitated by pre-existing relationships between the researchers and the managerial and research staff of the Children's Aid Societies. They, in turn, were connected to front-line agency staff serving street-involved youth, and so the multidimensional partnership began.

> **The solution:** *Provide street-involved youth with a creative outlet for sharing their experiences on the street.*

The YPP team found that community agencies were enthusiastic about the opportunity to host the web-based story-telling project. These agencies were chosen from among those participating in the research project that had sufficient drop-in clientele, ongoing educational and creative programming and available space.

Several local authors who write for a young adult audience or about issues affecting youth were identified by the research team. In particular, one team member, Katharine King, a short story writer herself, sought out writers to participate in the project. They quickly accepted the opportunity to run a workshop with street-involved youth. For each session, the research team asked the authors to devise writing exercises that would encourage the youth to interact amongst themselves and respond creatively to their experiences of street involvement.

Organizing, delivering, and learning

The creative writing workshops were constructed in consultation with the community partners to ensure that space was available and that the workshops were a good fit with ongoing youth programming (both in terms of scheduling and the content of existing creative programs). The project team was careful not to divert youth away from ongoing programs or to duplicate existing programs and, instead, designed the workshops to supplement regular scheduling.

Workshops took different forms in different agencies, and the project team remained flexible and listened to the needs of the individual hosts. For example, while one agency used the workshops to attract a large number of youth and acquaint them with the overall services available to them, another agency limited participation to youth with a particular creative interest in order to give more attention to each participant. Workshops were also introduced into the schedules of the agencies in such a way that ensured their capacity to continue the creative workshops once the funding for the project had ended.

The workshops themselves proved to be a learning process. The second workshop, for instance, did not go well. Held in a small space on a hot day, the workshop drew too many participants. The author struggled to stay on track and keep everyone's attention, while some of the participants were acting out or engaging in conversations amongst themselves. As a result, everybody seemed restless or uncomfortable.

Discouraged, but determined to make the workshops work, the project team went back to the staff at that particular agency to discuss what could be changed to improve the process. While no one wanted the workshops to feel like a classroom, everyone agreed that there was a need to establish some ground rules and boundaries to ensure respectful communication among the workshop attendees. The agency staff and the project team also decided to create a sign-up sheet for each event and place a strict maximum on the workshop size. Both the agency staff and the project team agreed that the workshops would be "works in progress", and that communication between both parties would remain open to ensure that adjustments, if necessary, could always be made.

In all, seven creative writing workshops were conducted, reaching over 50 youths, some of whom attended all of the workshops. Decisions about the direction of the workshops were made in face-to-face meetings between project staff and agency directors; this regular and frequent contact built trust and open communication. The agencies approved the choice of authors and the format of the workshops, but also gave the YPP team considerable flexibility. Furthermore, the agencies contributed food and space, but they also used the workshops as a forum to announce other ongoing programming for youth, thereby strengthening the agendas of all of the partners.

> **The approach:** *The research team combined forces with community organizations and local writers to create sustainable programs that would give street-involved youth a chance to express themselves creatively and learn about the other valuable resources available to them.*

"Toronto Youth Street Stories"

As the workshops progressed, the YPP team held weekly meetings to ensure that they were run smoothly. As the website was developed, these meetings were also used to prepare an agreed-upon plan for presenting material to the web designer.

The YPP team's relationships within the community proved useful for advertising the website: it was promoted in community agencies with posters, on cards given to youths after the creative writing workshops, through links of other websites and blogs and at academic conferences and workshops. Tracking of "hits" on the website began in early 2008 and, as of February 2009, the number of hits has reached 800.

> **The results:** *The "Toronto Youth Street Stories" website was created to display the work of the youth, explain the results of the YPP study, and direct street-involved youth to the health (and other) services available to them.*

In order to address an identified gap in websites aimed at street youth, the YPP team also developed a comprehensive list of services, including health services, for street-involved youth in the Greater Toronto Area (GTA). While there is information about street youth aimed at service providers and researchers, little of it was being designed to attract youth themselves. The goal of the YPP team was to provide needed information in a way that was accessible to youth, and to do so in a mode that empowers them to identify the resources available to them.

For the exciting website launch in the fall of 2007, a media and promotion coordinator was added to the YPP team to issue press releases to local media and to facilitate wide-ranging invitations to researchers, service providers and policy influencers working with street-involved youth in Toronto. The launch attracted a broad spectrum of attendees who enjoyed food, networking and a slideshow of the youths' creations, along with readings of stories and poetry by the youth themselves.

Such a multi-faceted project – from the initial study to the creative writing workshops to the launch of the website – would not have been possible without the dedication and collaboration of the researchers, agency managerial staff, front-line workers and, importantly, the youth themselves. Using both Integrated knowledge translation and End-of-grant knowledge translation methodology, the YPP leveraged partnerships to engage hard-to-reach audiences and give marginalized youth a voice.

Notes

[1] Fidler, Tara, Christine Wekerle, and Patricia G. Erickson. (2008). "The Youth Pathways Project (YPP): Childhood maltreatment and health outcomes among Toronto street-involved youth." *Ontario Association of Children's Aid Societies Journal, 52* (Winter), 25-32.

[2] Erickson, Patricia G. and Katharine King. (2007). "On the street: Influences on homelessness in young women." In N. Poole & L. Greaves (Eds.), *Highs and Lows: Canadian Perspectives on Women and Substance Abuse* (pp. 51-58). Toronto: Centre for Addiction and Mental Health.

[3] King, Katharine, Lori Ross, Tara Fidler and Patricia G. Erickson (2009). "Identity work among street-involved young mothers." *Journal of Youth Studies*, 12 (2), 139-149.

PARTNERSHIP PROFILE:
2005 CIHR PARTNERSHIP AWARD WINNER

Dr. Robert Brunham and Dr. Brett Finlay

For years, medical experts have feared a pandemic, a deadly outbreak of a new or mutated virus that would move swiftly through the population before any defences could be established against it. In 2002, Severe Acute Respiratory Syndrome (SARS) emerged in China and spread across the globe within a matter of weeks. With an estimated 438 cases in Canada, including 44 deaths, SARS placed unprecedented demands on the Canadian public health system. Nurses and other front-line health care workers became infected, raising concerns about the effectiveness of quarantine, while the sheer number of cases challenged regional capacities for outbreak containment and infection control.[1]

The Canadian scientific community moved quickly to assist in the fight against SARS. On April 12, 2003, the Michael Smith Genome Sciences Centre sequenced the SARS virus, succeeding before anyone else, even the huge Centres for Disease Control in the United States. Two weeks later, the British Columbia government provided $2.6 million in seed money for the SARS Accelerated Vaccine Initiative (SAVI). This national effort involved 12 universities and institutions across Canada, as well as the Protein Engineering Network Centre of Excellence, Health Canada, the Canadian SARS Research Consortium, a Biosafety level-3 lab in the United States and China's Guangdong Province Centre for Disease Control. SAVI was created with a mandate to develop an effective SARS vaccine as quickly as possible and to develop a new, accelerated model for scientific collaboration that would more effectively address public health needs.

Most research groups around the world chose a particular, familiar vaccine method for their research. SAVI, however, chose to develop three vaccine approaches simultaneously, only deciding which candidate should progress to human trials after a direct comparison of the three vaccines in relevant animal infection models.

"We realized immediately that, for [a vaccine approach to SARS] to be effective, we had to do things differently," recalls Dr. Brett Finlay, Scientific Director of SAVI, Professor in the Michael Smith Laboratories and departments of Biochemistry & Molecular Biology and Microbiology & Immunology at the University of British Columbia, and member of CIHR's Governing Council. "Traditional mechanisms for doing science were not going to work."

Those "traditional mechanisms" include the luxury of time. Standard granting procedures, from the start of the application to the receipt of funds for use in the laboratory, usually take more than a year; that schedule simply wouldn't work for SAVI.

"The development of vaccines and other therapeutic agents usually takes at least a decade and costs hundreds of millions of dollars," explain Dr. Finlay and Dr. Robert Brunham, Associate Director of SAVI, Professor in the Department of Medicine at the University of British Columbia, and

Provincial Executive Director of the BC Centre for Disease Control (an agency of the Provincial Health Services Authority). "But a practical solution for SARS was needed before the beginning of the next respiratory virus season."[3]

To deal with the SARS crisis, rapid funding mechanisms had to be established to ensure that appropriate research could be carried out in a timely manner. When SAVI was established, the Michael Smith Foundation for Health Research (the provincial funding agency for British Columbia) controlled and dispensed the $2.6 million that came from BC's provincial government. Using a five-member senior management committee of senior scientists, a rapid review mechanism was created to disburse grants. Short, focussed research proposals were solicited from the research community, and once evaluation of the proposals was complete, funds were immediately disbursed to successful applicants – usually 24 hours after the application was submitted.

SAVI's unconventional approach to the SARS crisis used an emergency management model, conducting activities concurrently (rather than consecutively, as is normally done), in a highly focussed and coordinated program, with designated leaders for key projects. Responding to emerging infectious diseases requires an approach that guides the science directly towards a practical solution to the problem, solving several puzzles in parallel. The SARS outbreak provided the perfect opportunity to develop such an approach, and this innovation won the SAVI team the CIHR Partnership Award in 2005.[4] "Collaboration between public health and science is key to finding solutions to public health emergencies," Dr. Brunham emphasizes. "A strong science foundation helps provide a strong response to public health challenges, forming the best defence against disease."

> "Collaboration between public health and science is key to finding solutions to public health emergencies."

SAVI established a senior management committee of its own that had significant experience in animal coronavirus vaccines and epidemiology, clinical trials and grant-funding mechanisms. Through a top-down management approach involving a management team and individual project leads, parallel research strategies were designed with vaccine development as the ultimate goal. This model allowed SAVI to identify vaccine candidates, handle the prospect of clinical trials, negotiate regulatory affairs and develop international collaborations concurrently.

From the beginning, it was clear that working in parallel would require SAVI's project leaders to keep in touch. Members of SAVI's research team were across British Columbia and the entire country. To maintain communication, the group set up a weekly teleconference system. "I was adamant that the calls would only last for one hour and would focus on critical matters," notes Dr. Finlay. "People knew that it was going to be a good use of their time."

Both Drs. Brunham and Finlay emphasize that these teleconferences were critical to maintaining the pace and momentum of the initiative. This regular communication allowed the SAVI project leaders to understand and hear how other parts of the initiative were run and, when overlap between projects occurred, these teleconferences enabled the teams to capitalize on each other's expertise. Scientific symposia were also held every six months to keep the entire SAVI group of collaborators aware of progress being made in different areas of the project.

Communication with the media was equally essential. The SARS outbreak received a great deal of media attention, and there was significant demand for updates on the progress of the research. SAVI hired a part-time staff member to act as liaison to deal with the media responsibly. A website was also developed to demystify the team's work and highlight the progress of the initiative on a weekly basis (**http://www.savi-info.ca**). The team wanted to handle (but not expand) expectations of their work, so a common message was discussed during the team's weekly teleconferences to establish a response that everyone could, if necessary, use that week with the media.

> ❝*All scientists were willing to contribute their expertise to work towards a common goal, with no individual gain immediately obvious.*❞

SAVI's experience in Canada shows that this paradigm of using "rapid response" research to address disease epidemics is working. The system was quickly accepted by all researchers who were approached for the SARS vaccine. In fact, scholars from other areas of academia also freely offered their time and skills to deal with related problems. "All scientists were willing to contribute their relevant expertise and a portion of their laboratory's resources to work towards a common goal, with no individual gain immediately obvious," explains Dr. Finlay.[5]

The lessons learned from SAVI also have the potential for shaping international cooperation and coordination during future disease outbreaks. The WHO played a pivotal role throughout the SARS pandemic, tracking the disease and convening meetings of researchers working on potential vaccines and diagnostics. This venue for networking is incredibly valuable. "In an ideal situation, expertise around the world would be coordinated, but this poses major logistical and political challenges," says Dr. Finlay. "International cooperation and coordination are needed to avoid significant duplication and redundancy of efforts, as well as to share progress. In the face of future epidemics, a coordinated international rapid response research approach will be essential to develop new ways of controlling these scourges."[6]

Dr. Finlay is quick to point out that the SAVI team was comprised of extraordinary people. "We had a wonderful group at all levels, and it really was their talents and hard work that led to SAVI's success." Ultimately, that success demonstrates how emergency management techniques, partnered with rapid response research, offer a highly effective approach to dealing with emerging infectious diseases.

"The lessons of SARS and SAVI ultimately are about communication and collaboration in the battle against emerging infectious diseases," concludes Dr. Brunham. "No man is an island – and this adage is one that scientists and public health professionals should take to heart in our ever-connected world."

Notes

[1] *Learning from SARS: Renewal of Public Health in Canada*, Health Canada, Ottawa, Ontario, 2004. Available from **http://www. phac-aspc.gc.ca/publicat/sars-sras/naylor**. Accessed February 2009.

[2] Hume, Mark. (2004, February 7). "In search of a SARS vaccine: 'It's been a heck of a ride.'" *The Globe and Mail*, p. F6.

[3] Finlay, B. Brett, Raymond H. See, and Robert C. Brunham. (2004). "Rapid response research to emerging infectious diseases: lessons from SARS." *Nature reviews. Microbiology, 2*(7), 602-607.

[4] Ibid.

[5] Ibid.

[6] Ibid.

BUILDING PARTNERSHIPS TO IMPROVE IDENTIFICATION AND TREATMENT OF ANTENATAL AND POSTPARTUM DEPRESSION

Angela Bowen (RN, PhD), Nazeem Muhajarine (PhD), and Fleur Macqueen Smith (MA candidate)
University of Saskatchewan

The Feelings in Pregnancy and Motherhood Research Team[1]
The Maternal Mental Health Program, Saskatoon, Saskatchewan[2]

Pregnancy is often a happy time for women, but it can also be a difficult or distressing one. To measure and understand depression during and after pregnancy, Dr. Nazeem Muhajarine, Chair of the Department of Community Health and Epidemiology at the University of Saskatchewan and research faculty member of the Saskatchewan Population Health and Evaluation Research Unit, and Dr. Angela Bowen, Assistant Professor in the College of Nursing at the University of Saskatchewan, co-led a team of researchers in what came to be known as the "Feelings in Pregnancy and Motherhood" study (**www.feelingsinpregnancy.ca**).

In 2005, the research team received CIHR funding to enrol 650 women in Saskatoon, Saskatchewan, during early pregnancy. The research team measured depression in each of the women twice during pregnancy and once in early postpartum in order to understand how depression may change over the course of pregnancy and the early postpartum stages. The researchers also sought to understand the determinants of depression and the factors associated with depression throughout the pregnancy cycle.

> **The issue:** *Pregnant and postpartum women who experience depression need timely professional help and treatment, but programs to provide these services are scarce.*

As the researchers developed the study, they knew that they would identify women who may need timely professional help. They did not want to be in the position of identifying women in need of medical services, however, without having the means to assist them. The idea that the study would provide information for developing better health-care services in the future would be of little consolation to the pregnant women sitting in the team's offices, looking for help. The researchers required partners who could provide the women with the assistance that they required.

Developing the Partnership

From the outset, the research team forged strong links with mental and maternal health care providers within the Saskatoon Health Region. The goals of this partnership were to inform key health care providers and administrators in the community about the Feelings in Pregnancy and Motherhood study, and the implications of identifying pregnant and postpartum women who screened as positive for depression over the course of the study. The partnership had two main objectives: 1) to develop a mechanism for referring women for urgent care and professional help, should they need it, and 2) to increase the awareness of antenatal and postpartum depression among primary caregivers so that they would be more likely to identify it and help their patients seek treatment.

When the study began, the team formed an advisory committee with members from the health region; they met twice a year, allowing decision makers to have an opportunity to provide regular input and learn about emerging findings.[3] The team also recruited a psychiatrist, along with committee members who were administrators and front-line managers of related programs. This process was facilitated by Dr. Bowen's strong credibility in the health region, where she had worked for 20 years as a registered nurse, manager and educator. She knew which people to contact and her connections made approaching managers and developing partnerships much easier, as she understood the context in which they provide health services. Furthermore, Dr. Muhajarine and Dr. Bowen are both well known in the community for their research commitment and passion for conducting research that is relevant to decision makers and informs policy and practice. Their enthusiasm is absolutely contagious.

Since advisory committee members are busy administrators in the health region, their time is used carefully by the research team; meetings are kept focussed, and only occur when the research team feels it is necessary to seek advice or keep the committee informed. The principal investigators and research staff, not the advisory committee, are the ones responsible for the day-to-day running of the study.

A key reason for developing the advisory group was to determine how to help the women who might screen as positive for depression during the course of the study. Early in the process, group members created a flowchart of all the imaginable ways that a woman could seek help, or how a study interviewer might get help for a woman in need. During the course of this meeting, the manager of Intake Services (from the health region's Mental Health Services) offered to serve as a first point of contact so that the interviewers could refer pregnant women in need for further assessment and treatment on a priority basis. At the time that this referral system was introduced, there were no specific mental health services in place for pregnant women, yet local studies conducted by Drs. Bowen and Muhajarine confirmed what other studies had found: about 800 of the 4000 women giving birth in the Saskatoon Health Region (or one in five) may be in need of such specialized services.[4]

Partnership leads to a new health service

Research also shows that women receiving such care within a primary health care setting report less stigma in getting help, and as the study progressed, different advisory committee members began to consider how they could provide those dedicated services.[5] At the time, the health region and the University of Saskatchewan had just opened West Winds Primary Health Centre, and it proved to be an ideal space for such a program.

The research team organized a half-day workshop with administrators, women who had experienced antenatal or postpartum depression, their advisory committee and other stakeholders to solicit input on program priorities and

> **The solution:** *Team up with research experts, women who have experienced antenatal or postpartum depression, and administrators from the health region to construct a new health service.*

potential services. Several facilitators were hired to assist with small-group discussions about how the program could work. Women who had experienced either antenatal or postpartum depression were placed in the same group, without any health professionals present, allowing them to feel more comfortable in openly discussing their needs and the obstacles that they had faced in the past. The ideas generated from this workshop were incorporated into the design of the program.

In September 2006, the Maternal Mental Health Program (MMHP) opened at West Winds. This program brings psychiatric and mental health care providers together once a month. The team had no funding for the MMHP, per se, so they were forced to be creative and bring interested and like-minded caregivers together to create a new service from existing ones. This process was made easier, however, since the team had already been working with many of the essential people through their advisory committee. The resulting program offers women consultation with a psychiatrist, Dr. Marilyn Baetz, who specializes in anxiety and mood disorders, and also provides access to a clinical health psychologist and a nurse therapist. Family medicine residents, psychology interns, nursing and other graduate students are also involved in the care, and the program has an advisory committee that includes health professionals and women who have experienced depression during pregnancy or after giving birth.

Communication and Knowledge Translation in action

To help keep people informed about the Feelings in Pregnancy and Motherhood study, the research team published newsletters four times per year. This newsletter was written by the study coordinator, Kathy Pierson, and Dr. Bowen, with input from Dr. Muhajarine, and was distributed to members of the advisory committee, the research team and health-care providers in the health region who were helping the team with recruitment (including family doctors, obstetricians, prenatal program managers and student health services at the University of Saskatchewan). Each issue included an update on the study's recruitment numbers, information about antenatal and postpartum depression, emerging findings from the study, names of the winners of the quarterly draws that were used to encourage recruitment, and other items of interest, such as information about the use of medication in pregnancy.

The research team publicized the opening of the MMHP in the newsletter and more widely to women and caregivers in Saskatoon. Dr. Bowen facilitated monthly meetings at the MMHP, discussing issues such as program staffing and how to continue to include clients in the program's operation, and minutes from these meetings were circulated in the health region to all committee members and appropriate health region administrators. This advisory group to the MMHP is now facilitated by a health region employee.

> **The approach:** *The research team leveraged partnerships to create a new health service out of existing ones, and to disseminate valuable information about antenatal and postpartum depression.*

Between September 2006 and September 2008, the MMHP cared for over 170 pregnant and postpartum women through visits to West Winds, telephone consultations and support to the local postpartum group.[6] This is a significant number of

women who previously did not have access to such specialized services. The development of this new health service demonstrates the well-documented impact that research can have when it involves policy makers and practitioners early and often throughout a study.[7,8]

The ongoing involvement of decision makers, at the advisory level and in the community, allowed them the time to develop a shared experience and trust with the researchers, which is necessary to work collaboratively. This service would not have been possible without the direct involvement of health region staff who were willing to re-organize and re-dedicate resources to support women participating in the study and, eventually, in the program. The initial findings from the study, which identified the need for such services, provided the evidence that these decision makers were able to use to strengthen their case with administrators to allow this new program to unfold.

Lessons Learned

The research team learned a few valuable lessons through this partnership. First, perseverance is essential: it takes a great deal of time and effort to develop credibility and to establish fruitful partnerships. Secondly, it is important to include decision makers early and often enough in the process to maintain communication and make use of their expertise (but not so often that they feel burdened, which can be a difficult balance to find).[9] Finally, the team strongly recommends that researchers budget enough funds for hospitality expenses for meetings; this is a way of thanking people for their involvement in the project. Goodwill goes a long way with partnerships and, as the team has already received more funding to evaluate the MMHP, the research team expects to develop other research projects, and to provide evidence for other services as their partnership with the health region continues.

> **The results:** *The direct involvement of policy makers and health region staff (who were willing to reorganize resources) enabled the research team to translate their findings into the development of a needed health service. Over the course of two years, over 170 pregnant and postpartum women have been cared for through the Maternal Mental Health Program.*

Notes

[1] The Feelings in Pregnancy and Motherhood Research Team: Rudy Bowen MD, FRCP (Psychiatrist, Professor, University of Saskatchewan), Peter Butt MD, FCFP (Associate Professor, Family Medicine, University of Saskatchewan), George Maslany PhD (Professor, Social Work, University of Regina), Kathy Pierson CCRP (Study Coordinator), Susan Morgan RN, RPN, BScN (Research Nurse), Michelle Jungwirth (Interviewer), Fleur Macqueen Smith MA (c) (Knowledge Translation).

[2] The Maternal Mental Health Program: Marilyn Baetz MD, FRCP (Psychiatrist, Associate Professor, University of Saskatchewan), Wendy Stefiuk RN MSc, ICLBC (former Manager of Nursing, Saskatoon Health Region), Nancy Klebaum RN, BScN, ICLBC (Manager of Nursing, Saskatoon Health Region), Nora McKee MD, CCFP, FCFP (Associate Professor, Family Medicine, University of Saskatchewan)), Dawn Phillips, Ph D, (Clinical Psychologist, Saskatoon Health Region).

[3] Antenatal Advisory Committee: Greg Drummond MSW (Director, Mental Health Services, Saskatoon Health Region), Sheila Achilles, RN, MN (Director, Primary Health Services, Saskatoon Health Region), Pam Woodsworth, RN, BScN (KidsFirst), Tony Winchester MSW (Intake Mental Health, Saskatoon Health Region), Marilyn Baetz (Psychiatrist, Associate Professor), Wendy Stefiuk RN, MSc, ICLBC (former Manager of Nursing, Saskatoon Health Region), Annette Gibbins RN, BScN (former Manager Healthy Mother, Healthy Baby, Saskatoon Health Region), Cheryl Hand RN (Head Nurse, Saskatoon Community Clinic).

[4] Marcus SM, Flynn HA, Blow FC, et al. (2003). Depressive symptoms among pregnant women screened in obstetrics settings. *Journal of Women's Health, 12,* 373-80.
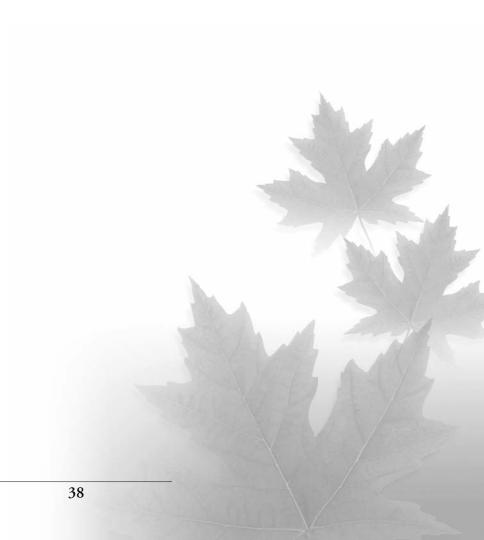
[5] Weissman, M. M., Feder, A., Pilowsky, D. J., Olfson, M., Fuentes, M., Blanco, C., et al. (2004). Depressed mothers coming to primary care: maternal reports of problems with their children. *Journal of Affective Disorders, 78*, 93-100.

[6] Bowen A., Baetz M., McKee N., and Klebaum, N. and the Maternal Mental Health Program (2008). Optimizing Maternal Mental Health Within a Primary Health Care Centre: A Model Program. *Canadian Journal of Community Mental Health, 27*(2), 105-116.

[7] Lomas, J., Fulop, N., Gagnon, D., & Allen, P. (2003). On being a good listener: setting priorities for applied health services research. *Milbank Quarterly, 81*, 363-388.

[8] Ross, S., Lavis, J., Rodriguez, C., Woodside, J., & Denis, J. L. (2003). Partnership experiences: involving decision makers in the research process. *Journal of Health Services, Research, and Policy, 8 Suppl 2*, 26-34.

[9] Macqueen Smith F., Muhajarine N., Vu L., Smith J., Delanoy S., Ellis J. (2008). Building partnerships to improve children's health. *Knowledge to Action: A Knowledge Translation Casebook.* Ottawa: Canadian Institutes of Health Research.

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PARTNERSHIP PROFILE:
2007 CIHR PARTNERSHIP AWARD WINNER

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Alberta Bone and Joint Health Institute

Hip and knee replacements are among the most successful surgical procedures for alleviating pain and restoring function and mobility for patients. As the population ages, longevity increases and obesity rates rise, the demand for these procedures is increasing. Patient care and service quality, however, can vary depending on such factors as location, socio-economic status and age.

Responding to the demand indicators and service issues, orthopaedic surgeons, public health care administrators, government policy makers and service design experts in Alberta launched a service improvement effort in 2004 that was groundbreaking in its level of collaboration and its scope. Working together with a common purpose, these partners dropped all preconceived ideas and examined every detail of hip and knee replacement care in Alberta and compared it to published research evidence. What emerged was a completely redesigned model of care based on the best evidence, with services standardized and delivered by multidisciplinary teams in a shared-care environment.

"Most people parked their individual agendas at the door and came together for the betterment of patients," recalls Dr. Don Dick, Chair of the Physician Advisory Committee for the project. "Everyone was part of the process and was taking each other seriously, so we were more engaged."

In order to test this newly-designed care continuum, they launched one of the most extensive health services delivery evaluations ever undertaken in North America – the Alberta Hip and Knee Replacement Project. This year-long effort brought together the Alberta Orthopaedic Society, Alberta's Ministry of Health and Wellness, health authorities in Edmonton, Calgary and Red Deer, and the Alberta Bone and Joint Health Institute (ABJHI) in an unprecedented partnership that won them the CIHR Partnership Award in 2007.

Completed in spring 2006, the project involved 1,125 hip or knee replacement patients who followed the new care path, and 513 who followed the conventional service approach. One-stop community-based Hip and Knee Replacement Clinics – a central feature of the new model – were established in Edmonton, Calgary and Red Deer. A multidisciplinary care structure was set up in each clinic. Patients in the new care path were referred to the clinics, and each was assigned a case manager. Standardized tools and processes were used throughout the process, including a referral template, patient contracts and treatment plans, evidence-based clinical practices and procedures, and scheduled patient follow-ups.

The results were remarkable. Patients in the new care path experienced greater improvement in general health and less pain after surgery. Fully 85% were up and mobile the day of surgery, and hospital stay was cut by almost a day and a half. Wait times were reduced dramatically for consultation and surgery. Most importantly, patients *and* health-care providers were more satisfied.

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The partners caution that the project's results were achieved in a controlled research environment wherein operating room time, hospital beds and staff resources were made available. "The project provided proof of concept, which was the purpose," says Dr. Cy Frank, an influential force behind the project, former Scientific Director of CIHR's Institute of Musculoskeletal Health and Arthritis, and now ABJHI's Executive Director. "These kinds of results – especially in reduced wait times – would be more difficult and take longer to achieve in the day-to-day operating environment of public health care where resources are strained."

Nevertheless, this new model of care is being implemented province-wide, recognizing the value that an evidence-based multidisciplinary approach - fully integrated and focussed on meeting care standards - can have for patients.

"One of the key issues is that the health system has become disconnected, with 'silos' of services – such as diagnostics, orthopaedic surgery, rheumatology, physiotherapy, and others – seemingly designed around that particular silo or service, rather than around the patient," explains Dr. Frank. "Our goal is to work with the health authority, our primary-care colleagues and other providers in the province to help realign the system so that it better serves all of our patients and helps make our whole system more sustainable."[1]

> "One of the key issues is that the health system has become disconnected, with 'silos' of services, seemingly designed around that particular silo or service, rather than around the patient."

Alberta Health and Wellness has committed funds to support the transition from the former practices to the new model. ABJHI is serving as an advisor and facilitator on the project to support the province-wide implementation.

The scope of this partnership is enormous, and it required the considerable time, commitment and passion of the many parties involved. Dr. Frank notes that the project was the culmination of hundreds of conversations and years of discussion. "It was as though suddenly the stars aligned in our favour," he says. "We were lucky to get the right leaders. People with the same goal realized that they needed each other. It was a big process leading up to getting the right people in the room, but plans grew exponentially from there."

A provincial Steering Committee was formed to provide project oversight, and the partners were careful to select one co-chair, Tracy Wasylak, from the health administration world and one co-chair, Dr. Gord Arnett, from the physician world.

"The physician-administrator co-leadership of the project was crucial for its success," says Dr. Frank. "We were also very lucky to have Tracy and Gord because they are such good communicators."

In fact, effective communication proved to be an essential component of the collaboration. While working on a project that was aimed at breaking down "silos", the partners became a model for breaking down silos themselves. The Steering Committee was built to be as inclusive as possible, and working groups were established for the component parts of the project. Information was

shared regularly among these groups and with the Steering Committee via teleconferencing, videoconferencing and face-to-face meetings.

Bringing together an engaged, multidisciplinary group and moving forward presents challenges. "Clarity of vision became very important," notes Ms. Wasylak. "We had many opportunities to be distracted by other agendas, and having a very focussed vision and purpose helped us stay on track. Physicians by nature are very independent, and we administrators want our way, too. Asking ourselves 'what are we here for?' kept us very focussed on improvement for patients."

> ❝*In a partnership, it's important to have leadership that supports one another.*❞

The purpose of this project was, indeed, improved patient outcomes, but it garnered intense media attention because of its potential to reduce wait times. To handle the media attention collaboratively, the partners established a communications committee with members from the health authorities in Edmonton, Calgary and Red Deer. Media inquiries were routed to assigned spokespersons based on subject matter and where and how the information would be used.

"Because we had this committee, we were able to form the right messages," recalls Ms. Wasylak, who also acted as a media contact. This collaborative approach enabled the partners to provide the media with messages that were balanced and accurate, without inflating public expectations or altering the scope of the project.
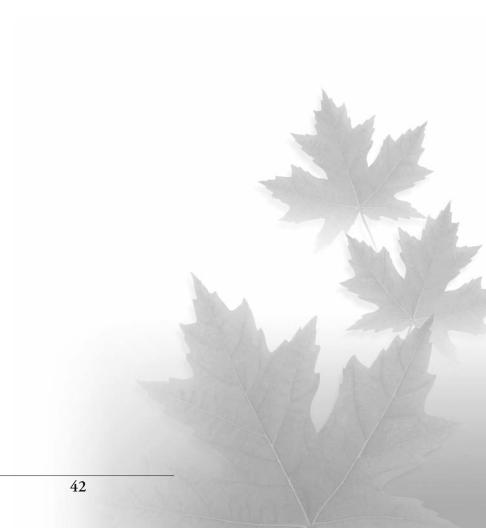
Overall, the approaches used by the partners throughout the entire project made their collaboration an exceptional example of cross-disciplinary partnership. What is most obvious, however, is the tremendous respect that the partners maintained for each other throughout the process.

"[In a partnership,] it's important to have leadership that supports one another," explains Dr. Ron Zernicke, Executive Director of ABJHI during the project. "It's easy to get discouraged and think that things aren't working, but it was a privilege to see how this co-leadership played out. The amount of time, effort, and diplomacy that was put into this project was incredible. I am in awe."

> ❝*People going into partnerships have to know that it is difficult, but worth it. Everybody can win – particularly the patients in this case, and that's important to know for our health-care system.*❞

Besides adhering to principles of teamwork and mutual trust, Dr. Frank stresses that a key factor in partnerships is being positive. "Communicate with people about the progress that they are making. Tracy, Don, and Ron are exceptionally positive and good communicators. They fed information back to the people involved in the project to let them know that they were making progress. You don't normally hear that in the health system."

The partners highlight communication, collaboration and consensus among stakeholders as essential ingredients for gathering and sharing the evidence needed to effect change. They offer the following advice: Be ready to leave your bias at the door, establish strong leadership that can be engaged as fully as possible and never underestimate the time it will take to dedicate yourself to the cause. Most importantly, don't give up.

"People going into partnerships have to know that it is difficult, but worth it," emphasizes Dr. Frank. "Everybody can win—particularly the patients in this case, and that's important to know for our health-care system. Change is possible."

Notes

[1] "Alberta Bone and Joint Health Institute." (2005). *AHRMR Research News*. Edmonton: Alberta Heritage Foundation for Medical Research. Available from **http://www.ahfmr.ab.ca/publications/newsletter/Winter05/www.files/inside/institute.htm**. Accessed February 2009.

An Evaluation Partnership: Ensuring Effectiveness and Translating Knowledge

Julie Bradette Co-ordination Assistant
CHSRF/CIHR Chair in Community Approaches
and Health Inequalities

Jocelyne Bernier, Co-ordinator
CHSRF/CIHR Chair in Community Approaches
and Health Inequalities

Yan Sénéchal, PhD Candidate
Department of Sociology, Université de
Montréal

Johanne Bédard, Researcher
Faculty of Education
University of Sherbrooke

Louise Potvin, Chairholder
CHSRF/CIHR Chair in Community Approaches
and Health Inequalities

As the Canadian Health Services Research Foundation/Canadian Institutes of Health Research Chair in Community Approaches and Health Inequalities, Dr. Louise Potvin directs a training and research program that investigates the relationships between social environments and health.[1] Social environments include elements such as our living and working conditions, the groups to which we belong, our income levels and our educational backgrounds; it is believed that they have a powerful effect on health that is independent of individual risk factors for disease. To better understand these "social determinants" of health and to reduce their potentially negative influence, part of Dr. Potvin's program deals with evaluating and improving the effectiveness of public programs and interventions that target the health of socially disadvantaged people.[2]

As Chair, Dr. Potvin encourages representatives from various public institutions and community networks to participate on her Steering Committee, which acts as an advisory body for the Chair. These representatives are also invited to take part in research and training activities, which encourages participation and feedback from all parties. These discussions and the connections that they foster amongst the participants of the Steering Committee help to keep the Chair in touch with the needs of the community, and this enables Dr. Potvin to adjust her research and training program as necessary.

> **The issue:** *A community organization wanted to ensure that one of its projects was meeting its objectives and having an impact.*

As part of this committee, a community organization called *Les ateliers cinq épices* and the *Table de concertation sur la faim et le développement social du Montréal métropolitain* (a network of more than 60 community organizations and coalitions working in the fields of food security and social development) submitted an application for the evaluation of an innovative school nutrition project. The project, called *Petits cuistots – parents en réseaux* (Junior Cooks – Parental Networks, or PC-PR), is designed to encourage healthy eating among children and their parents in disadvantaged Montreal neighbourhoods.[3] Led by nutritionists from *Les ateliers cinq épices* and working with teachers and

parent volunteers, PC-PR provides primary-school children with practical, interactive cooking and nutrition workshops. The ultimate objective of the PC-PR initiative is to promote healthy behaviours and attitudes amongst the participants by increasing their capacity to prepare nutritious meals. At the same time, however, the PC-PR is intended to enhance community development in each neighbourhood by connecting community workers with families and encouraging increased parental participation in school activities. Parents, for example, are invited to participate in the workshops with their children and are encouraged to join mutual-support networks through the community organizations in their neighbourhoods. The result is an intervention project that involves entire families in the process of preparing meals, while connecting them to the community-at-large.

The Evaluation Partnership

In response to the application for an evaluation of the PC-PR, an interdisciplinary team composed of researchers in health, education and nutrition was formed by Principal Investigators Louise Potvin and Johanne Bédard. With the goal of assessing the impact and effectiveness of the PC-PR project, the research team established an Evaluation Committee with *Les ateliers cinq épices*, the *Table de concertation sur la faim et le développement social du Montréal métropolitain*, and the PC-PR's two funding partners – the Montreal school board and the Lucie and André Chagnon Foundation. This committee has assisted the research team in carrying out its work in the seven schools that

> **The solution:** *Establish a multidisciplinary research team and Evaluation Committee to evaluate the effectiveness of the project.*

participate in the PC-PR project and in *Les ateliers cinq épices*. With the support of the committee, the research team visits each participating school at the beginning of the school year to inform the administration, teachers and non-teaching staff about the planned research activities for the coming year, as well as to discuss the preliminary analyses of research findings from the previous year. To stay connected and keep communication channels open, the research team has also participated in the annual meetings of *Les ateliers cinq épices* and the *Table de concertation sur la faim et le développement social*.

Meeting the Needs and Strengthening the Intervention

This research partnership, which has been in place for five years now, has enjoyed much of its success due to the effective communication practices that have been adopted with the help of the Evaluation Committee. The discussions within the committee have made it possible to remain open to any questions raised by the partners and to provide regular updates on the most recent research results to the various stakeholders.

Within the Evaluation Committee, representatives from the PC-PR project expressed the need for more training and support to make the intervention more systematic. The research team responded by working with the professional staff at *Les ateliers cinq épices* to strengthen the project by providing them with specialized training sessions. Specifically, one of the researchers worked with the organization's nutritionists to help them to more effectively tailor the workshop lessons to the

appropriate grade-level and to the desired nutritional skill set. Another researcher met with the social development officers from *Les ateliers cinq épices* to discuss the effect of the PC-PR intervention on the parents of the students.

The evaluation of the PC-PR project has also led to a new cooking, food and nutrition program (*Programme d'art culinaire, d'alimentation et de nutrition*) for *Les ateliers cinq épices*, and one of the members of the research team has provided the organization with ongoing coaching to help ensure that this new program is strictly in line with the priorities of the *Québec Education Program*, which is the official program of study for primary schools in Quebec.

> **The approach:** *The stake-holders involved in the project were engaged to guide research activities and to strengthen the intervention.*

Results Obtained

The research results have revealed that the PC-PR project has led to a positive effect on the nutritional attitudes, skills and behaviours of the children involved, while increasing the participation of their parents in school activities.

The evaluation findings show that the PC-PR encourages:

- the students to learn about nutrition and to develop culinary techniques that can then be applied at home;
- parents to participate in their child's school activities in a "non-threatening" space that values their contribution; and
- a place of listening, observation and exchange that supports school-family collaboration (by enabling school staff to work with parents and through the parents' investment in the school-life of their child).[4]

In addition, the social development practices and activities used in the PC-PR have stimulated the parents' interest in learning about nutrition, but have also contributed to strengthening the social connections in the neighbourhoods concerned.[5] These activities have included *Gourmets-Gourmands* workshops for parents that provide a venue for social interaction over a meal or delicacy prepared by one of the participants. Another example involves family outings that are connected to themes dealt with in the PC-PR project and provide a forum for sharing, which can then support the participation of parents in other activities. The PC-PR project also includes an annual graduation ceremony that recognizes the participation of the students and validates their senses of achievement and competence. All of these activities also contribute to inter-cultural exchange, as families who are new to Quebec may find that the nutritional and dietary practices in Canada are very different from the ones they had in another country.

> **The results:** *The education and social development elements of the project were strengthened. The research team and stakeholders worked together to adjust both the assessment and the intervention.*

Lessons Learned

Dr. Louise Potvin and Dr. Johanne Bédard are also members of the Research Team on Interventions to Reduce Social Disparities in Health, which was established in 2005 and is composed of researchers who are responsible for a variety of research partnerships. One of their objectives is to examine research practices in order to help develop tools and guidelines for these collaborations.

This team invited the members of the PC-PR Evaluation Committee to participate in a workshop on research partnerships. This workshop was designed to encourage the participants to share their experiences with the PC-PR evaluation, while enabling them to draw connections between research and practice. The discussions from this workshop helped the research team to identify four important conditions for successful partnerships:

1) design studies that reflect the concerns of the practitioners and the members of the community;
2) establish clear rules for the partnership;
3) ensure that the research partners are kept informed regularly; and
4) establish mechanisms for mediating expectations and ensuring consistent communication between the researchers and the practitioners.[6]

These conditions echo CIHR's concept of Integrated knowledge translation and were clearly evident in the evaluation partnership for the PC-PR project. Overall, by combining the forces of a multi-disciplinary research team with an Evaluation Committee, the evaluation of the PC-PR project was able to stay relevant to its stakeholders. Regular feedback throughout the evaluation and meetings with the schools led to adjustments in both the assessment and the intervention, enabling *Les ateliers cinq épices* to make the PC-PR project more systematic. Their specializations in health, education and nutrition allowed the research team members to support the objectives of the PC-PR project, and open communication practices ensured that the experiences of PC-PR stakeholders were recognized and valued. These positive experiences have led the partners to agree to continue their work together in a second phase of research on the evolution of the PC-PR project.

Notes

[1] The Canadian Health Services Research Foundation/Canadian Institutes of Health Research chairs were created primarily to provide a teaching and mentoring resource to graduate and postdoctoral students and to young teachers who are involved in applied research on health services and nursing. The objective of these chairs is to take advantage of the chairholders' research and teaching experience in order to build capacity in these fields (**http://www.chsrf.ca/cadre/chair_awards_e.php**).

[2] Centre de Recherche Léa-Roback sur les inégalités sociales de la santé de Montréal. "Researcher Profile." Available from (in French only): **http://www.centrelearoback.org/fr/chercheurs/profil_ch/membre_ch_11**. Accessed March 2009.

[3] Bisset, S. and Potvin, L. "Expanding our Conceptualization of Program Implementation: Lessons from the Genealogy of a School-Based Nutrition Program." *Health Education Research*, 2007, 22(5): 737-746.

[4] Bédard, J., Potvin, L., Couturier, Y., Desbiens, J.-F., Hasni, A. Larose, F., Lebrun. J., Lenoir, Y., Receveur, O. et Terrisse, B. (2008). *Rapport des recherches IRSC et CRSH (2005-2008) relatif aux différents recueils de données pour l'année 2005-2006, 2006-2007 et 2007-2008. Faits saillants pour les divers recueils réalisés durant les trois années d'études et rapports distincts par mesure.* Université de Sherbrooke, Faculté d'éducation, Centre de recherche sur l'intervention éducative (in French only).

[5] Ibid.

[6] Sénéchal, Y, Bradette, J, and Vibert, S. (2008) "Les pratiques réflexives dans la recherche participative en santé publique." *2008 Annual Conference of the Canadian Public Health Association.* Available from: **http://resources.cpha.ca/CPHA/Conf/Data/A08-064e.ppt**. Accessed March 2009.

INTERNATIONAL PARTNERSHIPS TO SUPPORT THE SCIENCE OF DRUG DISCOVERY: THE STRUCTURAL GENOMICS CONSORTIUM

Dr. Aled Edwards, CEO of the Structural Genomics Consortium

Despite massive increases in global funding of biomedical research in both the public and private sectors, fewer and fewer new medicines are being brought to market. In fact, only 17 new medicines were brought to market in 2007, which was the lowest number in decades. Part of the reason for this drop in medicinal development is that, despite incredible advances, new drugs that are tested through human clinical trials can still fail – and at great financial cost. This reality could become a serious problem for a Canadian public that relies on industry to produce new medicines.

The best long-term solution to this problem is to more accurately predict the effects of a new drug by increasing our knowledge about pharmacology (the study of the interactions between a living organism and drugs) and human biology. The skill sets required to make this solution happen, however, are normally segregated between academia and industry, so any approach must involve both academic and industrial scientists. This necessity often creates new challenges because collaborations between the sectors have been stopped by difficulties in identifying common goals or negotiating issues of potential intellectual property.

> **The issue:** *Bridging the work of academic and industrial scientists can lead to challenges in identifying common goals or negotiating issues of potential intellectual property.*

With this in mind, a group of research funders spanning industry, foundations, and government organizations conceived of the Structural Genomics Consortium (SGC). Led by Canadian researcher Dr. Aled Edwards, a world-leading expert in research on proteins, the SGC directs its efforts towards determining the three-dimensional structures of proteins that are relevant to human health, including those associated with cancer, neurological disorders, and infectious diseases like malaria. Information gleaned from the SGC provides insight into the functions of these proteins and their role in either safeguarding health or increasing susceptibility to disease. Most importantly, the SGC bridges the gap between academia and industry by depositing all of the identified protein structures into "protein data banks", which are considered to be part of the public domain (thereby avoiding issues of intellectual property), without any restrictions on their use.

Building the SGC

The SGC is a public-private partnership, involving more than 200 researchers from Canada, the United Kingdom and Sweden. It receives support from CIHR, Genome Canada (through the Ontario Genomics Institute), the Canada Foundation for Innovation, the Ontario Innovation Trust, the Knut and Alice Wallenberg Foundation, the Vinnova Swedish Agency of Innovation, Wellcome Trust, GlaxoSmithKline, Novartis and Merck.

In launching the SGC, the funders, which then included only one industrial partner, GlaxoSmithKline, first decided on the consortium's initial three-year mandate: to determine the structure of 386 protein structures relevant to human disease, and to place them into public databases with no restriction on use. Dr. Edwards was recruited to build the organization and carry out its objectives. Over this period (2004-2007), the SGC built laboratories at the University of Toronto, Oxford University (England), and the Karolinska Institute (Sweden).

One of the keys to the success of the partnership has been its management structure. The SGC is overseen by a Board of Directors, which has an independent Chair (currently Wayne Hendrickson, Columbia University), and a Scientific Committee. Both the Board of Directors and the Scientific Committee meet quarterly, and the funders are represented on each. In this way, the funders have had direct and ongoing input into the SGC's scientific and strategic directions, which more closely aligns the direction of the SGC with the missions of its funders. Each of the three laboratory operations are managed by a Chief Scientist; the Canadian site is overseen by Dr. Cheryl Arrowsmith.

> **The solution:** *Create a "public" organization that attracts the best scientists and shares their research results openly – with no restriction on use.*

The success of the SGC as an organization has been attributed to three factors. First, having labs in three premier academic institutions has enabled the SGC to attract outstanding scientists. Second, the non-proprietary philosophy of the organization facilitates collaboration, allowing those scientists to take advantage of the rich scientific environment in academia and the experience of industrial scientists. Finally, the activity of the SGC is managed carefully with oversight from both public and private sector funders; the scientists are therefore highly focussed on meeting their objectives.

Return on investment to its partners

In the first phase of the SGC, the organization was mandated to identify the structures of 386 proteins at reduced cost compared to academia or industry alone. The SCG reached this goal both ahead of schedule *and* under budget. The SGC is responsible for 20% of the world's output of human protein structures, and each is identified through the SGC for 50-90% *less* than in academia or industry. These savings are due to economies of scale, concentration of knowledge and the immediate communication of technical advances throughout the partnership.

> **The approach:** *As protein structures are identified, they are deposited into public "protein data banks" to be used by other scientists.*

The SGC partners, due to their different mandates, also have different objectives, and the SGC has managed to stay relevant to each. The SGC has maintained its relevance to industry, for example, by contributing about one-half of the new human protein kinase structures, among the most important targets for new medicines, into the public data-bases over the past three years. The SGC also published 150 peer-reviewed papers and engaged in over 100 different research collaborations, maintaining its links and contributions to the academic community. Lastly, some of the SGC

funders are very interested in knowledge translation and commercialization. The SGC has met these interests in a number of ways, including training and hosting dozens of students and post-doctoral fellows from academia and industry, and hosting workshops to transfer technology.

The future of the SGC and lessons learned

Based on the success of the SGC in the first three years of its existence, the funders approved a second phase for the consortium, investing additional funding to support the research until 2011. The goal for this second phase is to produce an additional 660 structures. The accomplishments of the first phase have also encouraged Merck and Novartis to join the SGC.

The objectives of the SGC remain focussed on providing information relevant to drug discovery, but the second phase of the organization has seen an expansion in the types of proteins identified. In Canada, the SGC laboratories have recently moved to co-locate with the Ontario Institute for Cancer Research, and both parties are excited to build a long-term scientific partnership.

In the long term, the SGC intends to serve as an intermediary between the public and private sectors, carrying and managing other scientific projects in the area of drug discovery that are of mutual benefit to each sector, and that require collaboration between them. The SGC is well-positioned to accomplish this goal because of its established reputation as an organization that provides a scientific environment in which scientists from different sectors and organizations can contribute their ideas and skills, knowing that they will be used to create knowledge for the public good, not for personal gain. As the first step toward this goal, the SGC is now leading an open-access public-private partnership involving the National Institutes of Health's Chemical Genomics Center and GlaxoSmithKline to generate pharmacological inhibitors of proteins involved in epigenetics research.

The results: *The SGC has successfully identified hundreds of protein structures at a cost of 50-90% less than in academia or industry alone.*

One of the strongest features of the SGC is its international nature. People take different approaches to problems depending on where they have been trained, so it is very constructive to have three different cultural backgrounds attacking the same problem.

The greatest lesson of the SGC model for partnerships is ultimately its capacity to function as the intermediary component in the interaction between academic and industrial pharmaceutical research. In the future, models such as this may perform the majority of the fundamental, pharmaceutically-relevant research in human pharmacology, physiology and toxicology. This research will support both industry and society's needs for targeted medications that succeed in clinical trials and eventually make their way to market.

PARTNERSHIP PROFILE:
2004 CIHR PARTNERSHIP AWARD WINNER

The Canadian Psychiatric Research Foundation and AstraZeneca Canada Inc.

The Canadian Psychiatric Research Foundation (CPRF) was founded in 1980 to fund mental health and addiction research across the country. Since its inception, CPRF has provided over $11M in research funding to 42 universities and teaching hospitals but, as a small charity that is reliant on private and corporate donations to help support this important research, CPRF struggles to build the resources needed to support the many research projects that deserve funding.

In 2001, AstraZeneca Canada Inc. came forward to suggest a research partnership with CPRF. Together with CIHR's Institute of Neurosciences, Mental Health and Addiction (CIHR-INMHA) and CIHR's Rx&D program[1], CPRF and AstraZeneca Canada Inc. launched the Neurobiology of Psychiatric Disorders and Addictions Program. Through this program, each partner contributes to the funding, so more research teams have been able to receive the support that would otherwise have been restricted to just a few.

The partnership between CPRF, AstraZeneca Canada Inc., CIHR-INMHA and CIHR's Rx&D program is a model for combining forces to increase the reach of research funding. To date, this Program has funded fourteen senior investigator awards and, as a result, the number of applications for funding to CPRF has doubled. The collaboration has also demonstrated how successful partnerships can multiply, as health researchers from across Canada have formed partnerships themselves in order to apply for the funding. This bridging of the public, private, and voluntary health sectors won CPRF and AstraZeneca Canada Inc. the CIHR Partnership Award in 2004.

CPRF has a long history of generating support and developing partnerships. The organization has partnered with community agencies to fund research that targets specific mental illnesses, and it has worked with a number of private sector partners to establish annual research awards. In 2006, for example, CPRF partnered with the Niagara Community Foundation to establish a Schizophrenia Research Award, and in 1999 The CIBC World Markets Children's Miracle Award was created to fund clinical research in childhood mental disorders. CPRF also enjoys support from family members of those who are experiencing mental health challenges. These parents, children and siblings understand the need for this research to find better treatments and cures for their loved ones. CPRF's partnership efforts allow two or more organizations to combine funds and offer resources and opportunities to the research community, while their continued contact with those who are affected by addiction and mental health issues ensures that those results are felt by individuals and the community.

This credibility has attracted a number of partners and supporters to the CPRF over the years. "Our corporate and private donors rely on CPRF's expertise and peer review," explains Jean Milligan, the Interim Executive Director of CPRF. "They usually have an area of interest, like Schizophrenia or Mood Disorders, and they trust us to make the most of their donations and to put the money where it needs to go."

CPRF also makes the most of the research that it funds. "We use researchers as much as possible to promote awareness and for knowledge translation," says Ms. Milligan. For example, the CPRF has developed a handbook series entitled "When Something's Wrong." The series includes: i) Strategies for

Teachers, ii) Ideas for Families and iii) Strategies for the Workplace. Building on this resource, CPRF tours Canada to deliver "Open Mind Workshops" that use these handbooks and current research findings to share knowledge and best practices with researchers, educators, practitioners and family members. To date, these tours have visited Vancouver, Calgary, Winnipeg, Quebec City, Halifax, Toronto and Ottawa.

> **❝[Our supporters] trust us to make the most of their donations and to put the money where it needs to go.❞**

Reducing stigma of mental health issues is also a core activity for CPRF. In 2004, CPRF won a United Nations Department of Public Information Award for its multi-media anti-stigma advertising campaign. This campaign offers print, TV and radio materials that clearly demonstrate the impact of stigma. The materials, created pro bono by Arnold Worldwide Canada, target the misconception that mental illnesses, such as depression or anorexia nervosa, are not "real" diseases but are simply character flaws or weaknesses. CPRF is committed to reducing stigma through key messages that are embedded into every CPRF workshop and event.

In 2007, the partnership efforts of the organization were honoured once again when the INMHA Partnership Award was bestowed upon CPRF at the awards dinner of the Fifth Annual CIHR-INMHA Meeting. The award was given to CPRF for its outstanding work in support of CIHR-INMHA's mandate, which includes supporting research to enhance mental health and to reduce the burden of related disorders.

Far from being finished, the CPRF continues to plan future collaborations. In 2008, the organization announced a new partnership endeavour that will see it join forces with Mental Health Partnerships of Canada (MHPC) to create a new national mental health charity. MHPC will expand fundraising activities and develop leading research projects in the fields of mental health, mental illness and brain injury while CPRF will bring its significant research, peer review and publishing capacity to the new alliance.

"Our alliance will create a charity for mental health on a scale with charities such as breast cancer, and heart and stroke," emphasizes Kevin McNeil, Chair of the CPRF.

> **❝Our alliance will create a charity for mental health on a scale with charities such as breast cancer, and heart and stroke.❞**

Working in partnership has been integral to CPRF's success. Over the past 29 years, the experiences of CPRF clearly demonstrate that much more can be accomplished through joint efforts than alone. Their mandate to fund all areas of mental health and addiction research opens up opportunities for a wide range of collaborations, and CPRF has learned that successful partnerships require clear communication and an understanding of expectations. Furthermore, the organization emphasizes that relationships work best when all the parties have a strong commitment to a common goal that benefits everyone involved. Partnership is about working together to complement each other's strengths and objectives.

CPRF looks forward to developing its collaboration with the Mental Health Partnerships of Canada and all other community, corporate and private partners to continue to provide valuable research funding and to find better treatments for mental illness.

Notes

[1] The CIHR/Rx&D Program is a partnership between Canada's Research-Based Pharmaceutical Companies (Rx&D) and CIHR, established to provide and opportunity for health researchers to work in collaboration with Rx&D companies. Research undertaken must be beneficial to all parties and have the aim of improving the quality of health of Canadians.

Positive Spaces, Healthy Places: An Innovative Community-Academic-Policy Partnership Moves Research into Action

Dr. Sean B. Rourke,
Scientific and Executive Director, OHTN
Scientist, Centre of Inner City Health
in the Keenan Research Centre of the Li Ka Shing
Knowledge Institute, St. Michael's Hospital
Associate Professor, University of Toronto
Adjunct Professor, University of Windsor

Jean Bacon
Director, Policy and Knowledge Transfer
and Exchange, OHTN

Ruthann Tucker
Senior Director, Community-based
Research Initiatives, OHTN

Housing and housing supports play a critical role in HIV prevention, and they are also powerful determinants of health for people living with HIV. Stable and appropriate housing, however, continues to be one of the greatest unmet needs of people living with HIV. The Positive Spaces, Healthy Places (PSHP) study – jointly funded by CIHR, the Ontario HIV Treatment Network (OHTN), the AIDS Bureau of the Ontario Ministry of Health and Long-Term Care and the Ontario AIDS Network – is the first longitudinal community-based initiative in Canada to examine housing stability and housing outcomes among people living with HIV. This comprehensive three-year study, which began in 2005, has also been the catalyst for capacity development in the area and for local, national and international partnerships that are leading to better housing and other supports for people with HIV.

Putting the pieces together

The HIV community identified the lack of stable, affordable housing as an urgent issue in 2002. At a meeting of Executive Directors of community-based HIV/AIDS organizations, participants noted that housing was the greatest unmet need among people living with HIV/AIDS and that access to housing supports, which ensure safety, health and dignity, varied across the province. The lack of research on the housing status of people with HIV, particularly in Canada, was a barrier to understanding their needs and planning for the future. The community needed rigorous data to make the case for investments in housing and support services.

The issue: *The HIV community identified the lack of stable, affordable housing as an urgent issue and the greatest unmet need among people living with HIV/AIDS.*

As part of its *Strategic Plan to 2010*, the OHTN began working directly with community champions, policy makers (in the areas of HIV, addictions, mental health, and regional planning), housing providers and researchers (with expertise in homelessness and mental health) to solve problems and to fill this gap. In 2004, a multidisciplinary, multi-sector partnership was formed; since then, all of the partners have been involved in every stage of the project, including identifying the research questions, analyzing results, identifying solutions and best practices, and sharing knowledge.

The objectives of this partnership are to:

- increase understanding and awareness of the housing needs of people living with HIV in Ontario and the impact of housing on health, quality of life and HIV prevention; and
- promote policies, programs, services and best practices that will increase access to safe, affordable and stable housing for people with HIV and people at risk.

The community-academic partnership component was crucial to the overall success of the study and the partnership; the community leaders were able to identify key community champions, while the academic leaders were able to identify experts working in related fields, such as mental health, homelessness, housing and urban planning. This combination of valuable skills and knowledge added strength to the partnership that none of the partners could have achieved alone.

Working together to have an impact

At the local and provincial levels, the PSHP partnership has already had a dramatic impact. It helped Fife House, a housing service provider in Toronto, secure $19 million in government funding to increase the supply of supportive housing for people with HIV. The partnership also helped another Ontario community-based AIDS organization, AIDS Niagara, obtain an additional $200,000 in annual funding for supportive housing through the Local Health Integration Network.

The solution: *Partner with multidisciplinary researchers, community champions, housing providers, and policy makers to make the case for investments in housing and support services.*

The links to researchers and the access to data provided by the PSHP helped to secure this funding. In fact, the PSHP findings are cited in the Ontario Human Rights Commission Report entitled *Right at home: Report on the consultation on rental housing and human rights.*[1] Furthermore, the partnership included expertise in knowledge translation and the issues faced by communities, ensuring that its findings were organized and presented in a way (i.e., by geographic area, by population, by income) that policy makers would find most persuasive.

The partnership has also successfully engaged policy makers from the addictions and mental health sectors; because of this link, people in Ontario with HIV are now explicitly eligible for a new provincial supportive housing program for people with addictions. The partners are now actively working with the Local Health Integration Networks in Ontario to share research and best practices, and to advocate for more investment in supportive housing for people with HIV.

The PSHP partnership is taking its success across the country. The partnership hosted a national Research to Action Symposium for policy makers, community-based AIDS organizations, people living with HIV, housing providers and researchers to explore the potential for developing a national HIV housing coalition. The OHTN is providing leadership to three other Canadian regions (British Columbia, Alberta and the Atlantic Region) to replicate the research with their respective populations. Partnerships and capacity-building with the Aboriginal, African and Caribbean communities have also resulted in two proposals for housing-related research that have been successful in securing funding from CIHR.

The PSHP is also moving beyond Canada's borders and has developed a close working relationship with researchers from the United States. As part of their environmental scan, members of the PSHP team[2] assessed experience in other jurisdictions. When they found articles and materials developed by the US-based National AIDS Housing Coalition (NAHC), they submitted an abstract to the annual NAHC conference; PSHP team members were invited to attend the conference and present their findings. This, in turn, led to invitations for NAHC staff members to participate in a Knowledge to Action symposium organized by the PSHP team.

These activities led to a more exciting partnership on housing issues. For example, at the 2008 International AIDS Conference, PSHP co-hosted the first International AIDS Society satellite session on Poverty, Homelessness and HIV/AIDS with NAHC, Housing Works Inc. and the San Francisco AIDS Foundation. More than 150 delegates endorsed a declaration asking policy makers to "recognize housing as a human right and address the lack of adequate housing as a barrier to effective HIV prevention, treatment, and care." The declaration was accepted by the International AIDS Society.[3] In June 2009, the OHTN-led team, NAHC and the Johns Hopkins School of Public Health will co-sponsor the North American Housing and HIV/AIDS Research Summit, where research teams will present new findings – including follow-up analyses and reports from the PSHP study – and develop knowledge exchange strategies to improve housing policy and access to supportive housing.

Making the partnership work

Several critical success factors make the PSHP partnership a success, and help to convey the message that "housing is health, and housing is good policy":

- the PSHP team has capitalized on the strengths of each partner: academic partners helped build a rigorous case for investing in housing to improve health; community partners contributed their in-depth understanding of how services work and how to engage and involve the community; and policy partners provided strategic advice on how to connect with and influence their peers;

- all members of the team were carefully chosen for their ability to influence peers and their willingness to work in partnership. All are full participants in the research team and the lead Principal Investigators are community leaders;

> **The approach:** *The PSHP team capitalized on the strengths of each partner, using the research of the academic partners to build a case, the in-depth understanding of the community to engage their peers, and the strategic advice of the policy partners to connect with decision makers.*

- all research interviews were conducted by trained peer research assistants (PRAs). The benefits of this approach included faster recruitment, more complete data collection and better retention of study participants. In addition, the project enhanced the quality of life of the people with HIV who became PRAs by providing opportunities for employment. The PRAs were so effective that the OHTN has now established a PRA research institute that will train more people with HIV to be involved in the research that affects their lives;

- the team has made effective use of a range of knowledge exchange strategies, including papers at conferences and in peer-reviewed journals; strategic think tanks and symposia that bring together community, policy makers and service providers; fact sheets that provide summaries of the study findings by region and by local health integration networks; one-to-one meetings with key decision makers; town hall meetings to engage individual communities, and a housing policy toolkit (in development). However, the most effective knowledge translation strategy has been involving policy makers and service providers on the research team;

- community members make most presentations, which reinforces their ownership of the data and their role in influencing practice. Ownership and control of research is particularly important in the Aboriginal community. The Aboriginal member of the research team has been involved in all aspects of the research, including advising on recruitment, developing questions, analyzing the data and ensuring that results are presented first to the Aboriginal community; and

- the team continues to learn from others. The relationship with the NAHC has been particularly helpful because that organization has advocated successfully for housing for people with HIV in the US, and some of its strategies – including the policy toolkit – can be adapted for use in Canada.

Lessons learned and future opportunities

The PSHP community-academic-policy partnership is essential to putting research into action. It has enhanced research quality and relevance to the community, and the team has been able to achieve results (such as more funding for housing, policy changes and changes in housing services) that would not have been possible if each partner had acted alone. On the strength of baseline and six-month findings, they have achieved these results before the study is even complete.

Through the process, team members learned lessons about building partnerships that are now being used to address other HIV issues (including employment, mental health and HIV/HCV co-infection) and to enrich learning opportunities for students. For example, it was important for the community to play a leading role in driving the partnership while identifying practical needs and issues. It was equally important to recruit academics who were committed to working collaboratively and who respected the wisdom of the community. The PSHP team advises others to recruit diverse groups; their large team was an advantage in terms of managing the tasks involved in the partnership and contributing varied expertise. The team has made a number of presentations, so its experience is now being used by others. Furthermore, the OHTN is actively promoting similar approaches in its Community-Based Research and other research funding programs.
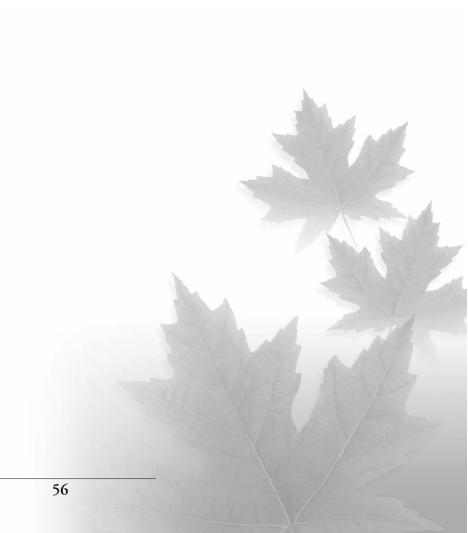
The results: *The PSHP partnership and study have helped Ontario community-based AIDS organizations secure funding for housing support services. The PSHP team has made national and international connections to share their success with other communities.*

The legacy of this successful partnership and the CIHR investment will be a lasting one. CIHR recently approved three years of additional funding, making PSHP the first housing research project to be re-funded. In addition to the dramatic change in housing policy and services achieved by the PSHP partnership and the development of the PRA institute, new national and international partnerships and the integration of many of the questions raised by PSHP into ongoing clinical and cohort studies suggest that there will be more examples of successful research – and successful partnerships – in the future.

Notes

[1] *Right at home: Report on the consultation on rental housing and human rights,* Ontario Human Rights Commission, Toronto, 2008. Available from **http://www.ohrc.on.ca/en/resources/discussion_consultation/housingconsultationreport/pdf**. Accessed February 2009.

[2] PSHP Team: Amrita Ahluwalia (Fife House), Steve Byers (AIDS Niagara), James Dunn (St. Michael's Hospital and University of Toronto), Saara Greene (McMaster University and Fife House), Dale Guenter (McMaster University), Michael Hamilton (Fife House), D. Hintzen (Fife House), Steven Hwang (St. Michael's Hospital and University of Toronto), Marie Kayitesi (Fife House), Jay Koornstra (Bruce House), LaVerne Monette (Ontario Aboriginal AIDS Strategy), Dave Pineau (Fife House), Sean B. Rourke (OHTN, St. Michael's Hospital and University of Toronto), Michael Sobota (AIDS Thunder Bay), Jim Truax (Fife House), Ruthann Tucker (OHTN), James Watson (OHTN and Fife House), Pius J. White (OHTN and Fife House).

[3] For more information on the process, along with a copy of the statement, visit: **http://nationalaidshousing.org/international-aids-housing-roundtable/**.