

Research with a Pulse

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Good Morning, and thank you for inviting me here today.

I'm here this morning speaking to you as a community activist. As a community activist, I think it's important that I tell you, or perhaps just remind you, that the community needs the university. One only has to think about the different changes that globalization, the dismantling of social safety nets, the privatization of public services, the different and the very dramatic changes that man-made and also natural disasters are having on our communities, to begin to understand the many different kinds of questions that the community desperately needs the university to address.

By the same token, I can say that the university needs the community. Without the interest, the support, and the follow-through of the community, all the research in the world will have little impact, and bring no real answers or any real solutions. Ideas alone are meaningless without the ability to see them through, and believe me, ideas that meet the real needs of the community will be followed through.

This is why I've titled my talk today – **Research with a Pulse**. I want to talk to you about the kind of research that makes a real difference, research that will have a real effect on people's lives, or at least the kind of research that tries to. I am talking about research that will move the public to care and to engage and research that will move politicians to act.

I used to think about research as being mainly about statistics. I will confess to you right here and now that, I did get a D or maybe it was a C- in my nursing statistics course. I have never really considered myself a researcher, but I have done research, and fortunately my first real-life research experience was a good one, it turned out to be research with a pulse.

This first experience was the 1992 Street Health Report. It was somewhat unique at the time, but in many ways it was just 'classical' community based research, and for me it was an extremely stimulating experience. I will tell you a little bit about this report, our research, our findings and some of the obstacles you could face in your own research. Then, I will give you a bit of a 'cook's' tour of some of the other research that I have been involved in which was, let's say,

controversially successful.

The Street Health Report

I was pretty new to the issue of homelessness when I began working at Street Health in 1989. It was an organization that was so close to the street, to the issues, to the people, and it responded in very creative ways to homeless people's needs. In fact, it was a homeless man who first coined the term "Street Nurse" as he hollered hello at us one day from across the street – it was a sign of respect.

So, after a couple of years of street nursing, banging our heads up against the walls of City Hall, provincial health care bureaucracies and hospitals, we realized at Street Health that we had a responsibility to better document both the health problems and the barriers to services – both structural and attitudinal - that were encountered by the people we were working with. So, we launched the Street Health survey, to be written by the 4 nurses who worked there, useful to the homeless community and their advocates and reflective of homeless peoples' experiences and their problems with the health care system.

How we did it

From inception to the final report, the survey project took over one year to complete. We formed a working group and partnered with the Institute for Social Research at York University who guided us through the process and the Toronto Public Health Department who provided data entry.

Key components of the work included:

- Development of a questionnaire that was both quantitative and qualitative and which ultimately took 1.5 hours for each survey participant to complete
- Preparation, which included an inventory of 100 sites to develop a sampling strategy, we had to create a definition of homeless, develop a pre-survey, and a random selection process

- Hiring and training of 15 interviewers
- Scheduling to ensure 2 nurses were on site during all interviews to handle health concerns or any crisis
- 458 individuals were interviewed at 29 sites over a 6 week period (December '91 to January'92)
- Reimbursement of participants

What we found:

Homeless men and women did not have different health problems than the housed population but their conditions were made more difficult by poverty and living circumstances. This was not rocket science but it was perhaps our most important finding.

- Homeless people had 4x greater prevalence of emphysema and chronic bronchitis
- 6x rate of epilepsy
- 5% had a brain injury (info that was offered unsolicited)
- 40% had been assaulted at least once in the last year (essentially half of all the women)
- 25% of these assaults were by police = 10% of the entire sample
- 21% of the women had been raped at least once in the past year
- 8.5 % of the women had been physically or sexually assaulted (including incest) in childhood (this response was also unsolicited)
- 27% had considered suicide
- 8% had attempted suicide in the last year
- 40% did not have an Ontario Health Card
- 25% had been provided treatment advice they were unable to carry out
- The homeless were 2x as likely not to have received dental care in the past year

These were pretty gruesome statistics.

What we did:

- Data analysis and we determined what recommendations flowed from the findings that would influence public policy.
- Printing of a report that would be colourful and easily read with sufficient copies for the community including homeless people.
- We hosted a community briefing in City Hall Council chambers followed by a press conference.

- And finally, distribution of the Report to various bodies (Board of Health, Ministry of Health, Police Services Board) and vigorous follow-up with deputations, meetings and media work.

What we learned:

That change takes a long time.

That, as Michael Valpy says “nurses have the highest believability quotient of all health care providers”. In fact, The World Health Organization acknowledged the importance of the community-based nature of this research.

And we learned, that when you offer criticism or suggestions for improvement to just about any body, of course it’s not always taken well, but there is usually some effort to address the questions. So, for example, when we criticized community health centres for not taking into account the needs of homeless people – that eventually changed. In fact, I went on to become the first Nurse Practitioner employed full-time in a Nursing Outreach Program that would specialize in homeless people’s health care needs in a CHC.

But, and there is a **big but** – should you ever criticize members of the police, at least in Toronto, be prepared for what happened to us. A special team of detectives was deployed to investigate the Street Health Report, detectives that were sent out to “reportedly” find the “bad apples” in the police force who were beating up on homeless people. They did this by going to community agencies that were the sites for our interviews and they asked staff if they knew any **client** that had partaken in our survey. Furthermore, they demanded to see our raw data (which we obviously refused). At the advice of our lawyers and our research consultants, our raw data – 458 survey questionnaires, each about 30 pages long were put into protective hiding – from the police.

Last month, nurses at Street Health had the following experience. A man entered their office, suffering a head injury. He lapsed in and out of consciousness. They called 911 immediately. They called again in 15 minutes. They made repeated calls. 45 minutes later an ambulance came. They have lodged complaints with the various police and EMS bodies.

I can't help but think there's a link – despite the years that have lapsed.

Housing is Health

Although the most sensational press coverage of the Street Health Report was related to the findings on abuse, in reflection we helped to prove the most obvious – that if you don't have a home you are more unhealthy. In my opinion there isn't a lot more research needed on homelessness to make the point that housing would go a long way to improve people's health status.

There is now ample evidence on the connection between housing and health but I would suggest that we have not used that evidence adequately. When we call housing a 'social determinant of health' that phrase sounds like academic lingo, it goes over the heads of most people. We need to show, literally show, how housing improves health and that would be research with a pulse.

I'd like to move from the Street Health Report and begin what I'll call a 'cook's tour' of some other research initiatives I have worked on.

The One Percent Solution and the Disaster Declaration

I have to admit to being totally oblivious to the political events in 1993 when the federal government cancelled its National Housing Program – and I was a Street Nurse!

However, as conditions got worse, and we saw clusters of deaths, the return of tuberculosis, malnutrition, mass outdoor sleeping, and the horrible effects of crowding in shelters, the light bulb finally went on and I joined with several colleagues to form the Toronto Disaster Relief Committee. In the summer of 1998 we wrote a report called the State of Emergency Declaration which used statistics and referenced the UN Charters that Canada had signed. It was a passionate document, at a very basic literacy level and it was to the point.

Then, in October 1998 we held a press conference and declared homelessness a **National Disaster**. What we saw was not unique to Toronto. We believed that

Toronto was the canary in the mineshaft of homelessness in Canada. We released the **State of Emergency Declaration (www.tdrc.net)**, and we called for two things:

First, that federal emergency relief monies be released to communities across the country so they could provide disaster relief for their rapidly growing homeless populations. This effort is not unlike what is happening within the United States in the wake of Hurricane Katrina;

Second, we called for a long term solution, the 1% solution – a National Housing Program where all levels of government would spend an additional 1% of their budgets to build affordable housing. The One Per Cent Solution originates from **research** done by Professor David Hulchanski, who determined that when our federal, provincial, territorial and municipal governments were allocating money to social housing they were spending on average 1% of their budgets.

So, here's the pulse:

The first item essentially occurred. Homelessness in Canada was catapulted on the national and international scene. Prime Minister Chretien appointed Claudette Bradshaw as our first ever **Minister Responsible for Homelessness** and 'SCPI' (Supporting Community Partnerships Initiatives) monies were rolled out across the country. So, Canada had the distinction of having a Minister Responsible for Homelessness but not a Minister with full responsibility for housing! The hundreds of millions of SCPI dollars were, in effect disaster relief monies.

Regarding the second point – we are now very close, especially with the Layton-Martin budget deal that includes \$1.6 billion for housing and Minister Fontana is poised to release Canada's first Housing Framework document which could lead, finally, to a national programme.

The importance of historical research

We can always learn from our history whether it is 10 years ago or fifty. We refer to history a lot. So, we often remind people what it was like when we had no

national housing program.

In 1947 Toronto Mayor Saunders took out an ad in a Toronto newspaper warning people not to come to Toronto. Why was that? We had no national housing programme.

In our history we once had a national programme and it created thousands of units per year. There are ways we can show that. In every community those homes are there.

The Disaster

I know that people across the country had great hopes for the 1999 Ann Golden Report Taking Responsibility for Homelessness also known as the Mayor's (Lastman) Homelessness Action Task Force. The Report is 1" thick and had 105 recommendations. Today, 6 years later, the report's first recommendation that the City "appoint a Facilitator for Action on Homelessness for a five-year term, who will report to the Mayor and Council" **was never implemented**. Needless to say, many other Task Force recommendations, such as the construction of 5,000 additional supportive housing units over a 5-year period, did not materialize.

Conditions have worsened. We have seen an increasing reliance on emergency shelters, we have seen disease outbreaks and infestations, we have seen a climbing death toll, and the development of more outdoor encampments by people who want to avoid a clearly unhealthy shelter system.

So, when more traditional methods of advocacy such as deputations, press conferences, inquests, even touring the Medical Officer of Health to shelter sites did not bring in the changes we needed to respond to this crisis, we began to employ more unorthodox research techniques.

Secret Video Footage

It was actually filmmaker Shelley Saywell, who while working on a film about homelessness, called Street Nurse, first captured the shelter conditions in Toronto that violated the United Nations standard for refugee camps.

Unbeknownst to me the footage was taken and when I was shown the footage – the horror.

- Over 100 men and women – people sleeping on the floor
- lights kept on all night because bodies were so close together
- a stagnant and airless basement
- 4 people in the space that one person should have, according to the UN

It was clear we had to do something with this footage. If there had been a fire and we had stayed silent we would have been responsible.

The pulse: We used it, respecting privacy issues, and within a month this facility was given assistance to improve its conditions.

Later that year when it was apparent the City would not extend its remediation of shelter conditions beyond this one single case, we rented our own secret camera from Spysshop and took to the streets and to the shelters again. This footage showed line-ups reminiscent of the depression era, and inhumane images of emergency shelter conditions that did not meet the UN standards. As Dri from Tent City said “if people saw animals kept in these conditions – they would be so upset.”

The Shelter Inspection Report

In June 1999, shelter capacity in Toronto had exceeded 90%. City Council passed a motion directing staff to open additional shelters whenever shelters reached the 90% capacity. **It never occurred.**

In June 2000, TDRC first called upon Toronto’s Medical Officer of Health to carry out a special investigation of health standards in the shelter system to ensure they met international public health standards. **No such inspection was done.**

In 2001, TDRC took the Medical Officer of Health on a tour of the shelter conditions. **No changes were made.**

In 2001, Toronto had its first tuberculosis outbreak. **Three homeless men died.**

In 2002, TDRC released secret video footage showing the horrific conditions.

In January 2003, TDRC formally requested that the City's Shelter Housing and Support Division assemble a team of independent experts who would enter the hostel system to investigate shelter conditions. **We received no reply.**

So these events and many more led us to create our own Shelter Inspection Team that heard evidence from homeless people. In addition, several homeless people were equipped with a checklist to survey some shelters. For example, using a piece of rope they measured space between beds/mats, they looked at fire exits, the number of showers, the number of working toilets, etc.

The Shelter Inspection Report is simple and to the point. It is available on our web site www.tdrc.net.

Now, to the pulse of this research: the City's Shelter Standards now reference some of the United Nations standards for space and SCPI monies have been used to upgrade the conditions in many Toronto shelters. As my colleague Michael Shapcott says "homeless people were made more comfortable by the SCPI money but no less homeless." A reminder why we need to keep up the pressure for housing money.

I should note that in May 2003 when the Shelter Inspection Report was released, Toronto was facing its first Severe Acute Respiratory Syndrome (SARS) outbreak. SARS is a deadly reminder of the life and death situation that face people forced to live in congregate living situations.

Plagues

I use some literary license when I talk about plagues, but tuberculosis is historically known as the 'white plague'.

In many cultures there are legends about pestilence. In Russia it was the Pest Maiden who carried disease throughout villages causing peasants to fall dead before her. After a visit from the Pest Maiden, funeral processions clogged the streets. Occasionally a peasant would fight the Pest Maiden off and she would go

into the forest to wait for another day and another opportunity to attack.

Andrew Nikiforuk uses imagery like this in his book The Fourth Horseman to describe the cyclical nature of plagues, scourges and emerging viruses that erupt when social disasters like overcrowding, hunger and homelessness devastate a country. He describes the Fourth Horseman as one of the riders of the Apocalypse, who is both pestilence and death, riding into our lives with epidemics, pandemics and death.

Bedbugs, Tuberculosis, West Nile, Norwalk, SARS, Pandemic flu. These are today's scourges that require more research. Why? To prove that congregate living is deadly and housing is the solution!

In 2003 we once again entered the area of community research by holding an inquiry into TB where we heard primarily qualitative evidence on the issue.

The pulse - it led to an inquest and it led to many community and hospital sector workers being very adequately prepared on the issue to provide expert testimony at the subsequent Inquest. Our report is called TB or not TB? and is available on www.tdrc.net

Death on the Streets of Canada

In 1999, University of Toronto Professor David Hulchanski prepared a document called Death on the Streets of Canada. It was presented to the United Nations Human Rights Committee. It pointed out that Canadian government inaction was leading to a dramatic increase in morbidity and death.

The pulse – it led to comments of concern by the UN Committee and again placed the issue on the international agenda.

Today, we continue to track homeless deaths, adding 8-10 names per month to the Homeless Memorial board at our monthly vigil in Toronto. To date, no government body is responsible for tracking homeless deaths.

Two weeks ago, a 59-year-old homeless man by the name of Paul Croutch was brutally beaten while in his sleeping bag sleeping in a park adjacent to the federal Moss Park Armouries in Toronto. Three army reservists have been charged with second-degree murder. We are calling for this crime to be considered a hate crime. It's not the first time we have seen homeless people murdered in Canada. But it should be the last.

Once again, we in the community are desperately seeking research support on this issue.

Can Research be the Solution?

I'm inclined to say it can be part of the solution.

I'd like to give you three examples.

1) The Tent City Story

From tents to shacks with woodstoves, insulation to pre-fab housing – these were some of the methods used to help support and transform a community. I can't say that we did research on these substantive changes to people's living conditions at Tent City but it would have been possible.

But there were three pieces of research that did happen.

The first - the Tent City Census. At one point Tent City was growing so rapidly we did a census of our own to track the numbers and we distributed shower bags in the process as a gift for participating. It was a good thing we did – only a month or two later the forced eviction happened and we were able to say that Tent City consisted of 120 people, 14 dogs, 50 shacks, etc – and we used that data to fight for their housing. And we won.

The Second – the pre-fabs. By bringing in pre-fab housing for anywhere between \$1,000 to \$10,000 per unit we were able to show that people would choose to live in such a dwelling instead of in a tent, on the street or in a shelter. The cost of keeping someone in a shelter per month: between \$1140 - \$2100 per month

compared to zero at Tent City, once the housing was provided.

The Third - and perhaps the most important research on Tent City - the Rent Supplement Win.

- 112 formerly homeless people now in housing (73 men, 31 women, 4 couples)
- 23% now volunteering, 16% in school, 11% trying to find employment
- Cost: \$11,631 pp per annum (including their social assistance) compared to \$16,156 pp per annum to keep someone in a shelter
- 80% are eating better
- 93% stress the importance of their housing support worker

In this case terrific research was done by the City of Toronto that adds to the point that **housing is health**. This report is also available at www.tdrc.net

2) Hunger and Malnutrition

Even when people become housed, we know they remain hungry. Important work is now underway by OCAP (the Ontario Coalition Against Poverty). Their campaign around the special diet allowance available in Ontario for people on social assistance has now put more than 4,000 people in a more adequate position to afford food. In organized “diet clinics” around Toronto and southern Ontario, health providers are assessing people for this \$250 allowance. An example of the impact: a family of 6 on social assistance receives an additional \$1500 per month once the diet forms are completed by a licensed health practitioner.

At the same time doctors at St. Michael’s Hospital are using the opportunity to research people’s food intake prior to receiving the dietary allowance.

As of August, 8,353 Toronto welfare recipients were receiving the \$250 monthly special diet allowance – an increase of at least 30%.

3) Report Cards

TDRC is the secretariat for the National Housing and Homelessness Network. We regularly issue Report Cards – on how the federal government is doing

province by province and in the territories, on their promises to fund and build housing. In fact, politicians have become very sensitive about our Report Card, often questioning their B-, C or D, hoping to get a higher grade I guess.

Sometimes it's as simple as number crunching to get the attention of politicians.

In conclusion, where are we today?

Well, we've researched homelessness to death, literally.

We still do not have a "coherent policy of national standards to ensure that the right to adequate housing is enjoyed by all and particularly by poor and disadvantaged groups, such as low-income women." (Canadian NGOs submission to the UN Committee on Economic and Cultural Rights Working Group, May 16, 2005).

We have a predicted federal surplus of maybe \$10 billion dollars. Hopefully \$1.6 billion of that will fulfill the housing portion of the Layton-Martin budget.

We have some provincial governments still refusing to release promised dollars for housing. For example, in Ontario, 63 units were developed in the first 3 years of the federal-provincial Ontario program. They should have created 8,592. In late August, the province finally announced how they would begin allocating those monies however analysis shows that units created will be heavily weighted towards home ownership. This was Ontario's 11th announcement (reannouncement) and report of allocations since 2001. Announcements and allocations on paper do not always translate into affordable housing starts.

But, we are stronger and more sophisticated in our lobbying efforts than ever before. Our challenge is to get the research that supports our efforts – whether it is in the area of childcare, nutrition, poverty or homelessness.

In four days the federal-provincial-territorial housing ministers will be meeting in Nova Scotia. We will be there! We have a tradition of building a house, a straw-bale house, a house of blocks, to show them what they should be doing.

In closing, I want to leave you with these questions.

Can research help to house our people?

Can research help to feed hungry families?

Can research prevent the catastrophic assault of the approaching pandemic flu?

Can research quantify the extent of injury of various social policies – like workfare or reduced employment insurance benefits, or delisting of services?

Or quantify the benefits of universal child care, public access to health care, expanded home care programs?

Can universities and communities collaborate so that research can be a tool to help recharge activism? The Dalai Lama speaks of meditation as a form of recharging – so one can then move to implement ideas into action. I think the same could be said for research, that it can provide the fuel, the energy, the pulse if you will for action, for social change.

Check with delivery